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Collective social capital: A study of new public health and end-of-life care

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Lay summary

The hospice and palliative care movement came into being to highlight and meet the needs of those dying and their families. It provided a new model of holistic care where the physical needs of the dying person were considered alongside the emotional, spiritual and social needs of them and their family.

Although the hospice and palliative care movement has made significant changes to the experiences of those dying around the world today, there have been criticisms of the movement, relating to the inequality of access to services by many marginalised groups and of the increasing role of professionals in care, seen to be taking over roles where traditionally communities would have supported people.

This study explored a new project designed to bring communities back into the care of the dying. This project, Compassionate Neighbours, was supported by a hospice but the members of the community taking part did not become formal hospice volunteers, instead remaining as lay members of the community.

A range of methods was used to gather data, aiming to hear from different people with different points of view. It showed the steps the project went through to get started and the range of impacts for those involved. Further to this, a set of principles that underpinned the whole project was demonstrated. These principles were: a shift in the power dynamics between participants in the project, including with the hospice, the expression of reciprocity throughout relationships in the project and the development of a sense of agency amongst participants. Agency for participants was understood as the ability to act on and change circumstances for themselves and others, and to appreciate the impact of these changes.

This study is important because it allows a new understanding of how people and organisations can relate to one another when power dynamics in relationships are acknowledged and changed. These relationships that take place in a more equal way allow people to express care and support reciprocally, rather than the one way nature of many relationships in healthcare. This is important for other people and organisations wanting to undertake similar work to this and also, more generally, for healthcare institutions such as hospices to reflect on how they can engage with communities on a more equal footing.

Abstract:

Background:

An appreciation of the broader social determinants of health and wellbeing has led to the inclusion of new public health principles and practice within health and social care. End-of-life care has been no exception and there exists a favourable policy context, significant body of theoretical work, substantial practitioner interest and numerous practice examples. Despite this context, there has been little empirical exploration and the approaches remain poorly characterised.

Aims and objectives:

The aim of this study was to understand the impact a new public health approach to end-of-life care project can have when initiated through a hospice. Specifically this study sought to explore how a compassionate community project is experienced, what tensions exist, what processes support or impede the work, what specific challenges such a project developed from within this sector presents and what learning exists for the wider field.

Methods:

A mixed methods study employing multiple methods of data collection was performed. Data collection methods included: interviews; focus groups; participant observation; documentary analysis and service records. Ethics approval was obtained. Data were analysed according to modified grounded theory and using online software tool Dedoose.

Results:

Twenty-one interviews, two focus groups and 19 episodes of participant observation were conducted, 11 documents and service data on 180 Compassionate Neighbours and 173 Community Members were also included. Six key actions facilitated integration of new public health approaches with service provision approaches. Impacts from the work were wide ranging and included a reduction in loneliness, improvements in wellbeing and changes to hospice practice.

Further to this, three underlying drivers emerged that underpinned the work as a whole. They were seen to translate the observed actions of the project into the

impacts and included: altered power dynamics, expression of reciprocity in relationships and the development of agency.

Discussion:

The three drivers allow a deeper appreciation of the factors involved in the development of a compassionate community. The redressing of power dynamics within traditional provider-recipient relationships allowed for more equity, and created a space for reciprocal and mutual relations to emerge. Not only were these reciprocal relations observed between those at the end of life and those visiting them, but also between participants in the project and the hospice. In order to adequately capture these new perspectives offered through this study, a new term *collective social capital* is introduced. This moves beyond existing conceptualisations of social capital in end-of-life care to provide novel perspectives on the role of reciprocity and interdependency between the lay and professional worlds.

Conclusion:

This study provides a reflexive and critical account of the processes and impacts of compassionate communities work in practice. It situates reciprocal relationships as its foundation and forces an assessment of the nature of power and agency in all interactions. Through the presentation of the new concept of collective social capital, it presents a collaborative and interdependent path forward for new public health and end-of-life care in the future.

Declaration

- a) I have composed this thesis myself
- b) This work is my own
- c) This work has not been submitted for any other degree or professional qualification
- d) All included publications are my own work except where indicated

Elizabeth Sian Sallnow

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Abbreviations

CD	Community development
CM	Community Member
CN	Compassionate Neighbour
DBS	Disclosure and Barring Service (criminal records check)
Doc	Document
EOLC	End-of-life care
GP	General Practitioner
HIV	Human Immunodeficiency Virus
In	Interview
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NNPC	Neighbourhood Network in Palliative Care
PDM	Practice development meeting
PO	Participant observation
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Chapter 1: Introduction

This chapter gives an introduction to both the field of study and the dissertation. Changes in health and social care are presented to contextualise the emergence of new public health approaches, as one solution to the broad challenges faced today. The development of this movement within end-of-life care is introduced and the key drivers for the movement presented. In the second section of the chapter, an outline of each chapter is given to orientate the reader to the dissertation.

1.1 Background

Palliative and hospice care emerged as a compassionate human response to the experiences of those dying in a medicalised context at the end of the last century. In the years following this, palliative care has become a mainstream component of healthcare and has led to a revolution in care focused on the dying. Pain relief at the end of life has been made an international priority (Knaul, Farmer, Krakauer, *et al.*, 2017) and calls made for universal access to services to be a human right (European Association for Palliative Care, 2013). Notwithstanding these achievements, in the UK palliative care services still fail to reach many marginalised communities (Care Quality Commission, 2016), reports of the lack of compassion and dignity for many as they approach the end-of-life are commonplace (Francis, 2013; Leadership Alliance for Dying People, 2015) and changes in demographic profiles and illness patterns suggest demand for care will only increase (Etkind, Bone, Gomes, *et al.*, 2017).

The changing environment and context for end-of-life care is reflective of broader societal shifts and answers to issues are increasingly being sought outside the traditional biomedical or clinical sphere. Narratives relating to community participation or community cohesion are suffusing public documents from research practice (Brett, Staniszewska, Mockford, *et al.*, 2014) to neighbourhood regeneration (Purdue, 2001) and although these approaches enjoy long traditions in many varied fields, it is the prominence they assume within health and social care that represents the recent change. The Office for National Statistics began collecting data on the levels of social capital throughout the UK from 2015 (Office for National Statistics, 2015a) and NICE released their second guidance supporting community engagement in healthcare in 2014 (National Institute for Health and Care Excellence,

2014). Further to this, initiatives such as the Big Society (Cameron, 2010), the random acts of kindness initiative through Transport for London (Landy, 2011) and the recent report on importance of kindness by the Carnegie Trust (Carnegie Trust, 2017) demonstrate the mainstreaming of such perspectives and approaches into the wider sphere of public consciousness.

There are a number of questions to be reflected upon as these approaches gain prominence. Does this represent a new attitude or response to contemporary society, or does this represent a return to something that once existed but has since disappeared? Do these changes represent societal or individual level change, or a shift in the language used by politicians and others? These issues are subject to discussion and in many ways echo the much older debates relating to the relationship between individuals and state, the position of lay and indigenous knowledge and the meaning and role of community.

Regardless of the origin and present day context of these debates, the end-of-life care movement similarly finds itself encountering these new or evolving narratives. One response of the field, or of those close to it, has been the development of a new public health approach to end-of-life care, commonly known in the UK as the compassionate communities movement. Started in the late 1990s, this movement brought public health and end-of-life care together explicitly. It now forms a wide movement encompassing civic action, reform of healthcare institutions and local community action. It challenges the perceived professional dominance at the end of life, to empower communities to support those dying among them, to support the expression of compassion in society and to privilege the role of community and lay knowledge in issues relating to death, dying, loss and care (Kellehear, 2005). Surveys of public attitudes would seem to suggest the general public is supportive of these moves. A recent ComRes survey (National Council for Palliative Care, 2017) showed that members of public feel communities should play an active role in the care of family and friends dying and this is not just a job for professionals, even in relation to the issue of administering subcutaneous injections for family or friends dying at home.

A new public health approach to end-of-life care has developed a significant support base since its early theoretical development nearly two decades ago and today

examples of these approaches can be seen in numerous countries around the world (Sallnow, Kumar and Kellehear, 2012; Wegleitner, Heimerl and Kellehear, 2016). Whilst the proliferation of practice examples allows the approaches to be developed and experienced in different settings, the empirical evidence base has not kept pace. Questions regarding the experiences of those participating in such projects, the impacts such work can have and the contextual barriers and facilitators that support or hinder the work are unexplored and uncharacterised. This therefore is the next essential step for the field; to understand how the lived experience compares to the aspirations of the approach.

1.2 An introduction to the dissertation

This dissertation is comprised of ten chapters. A brief overview of each chapter is provided by way of introduction.

Chapter One: Introduction serves to introduce the reader to the field of new public health approaches to end-of-life care and to set this within the broader societal setting, whilst providing an orientation to the layout and structure of the dissertation.

Chapter Two: The context of the research describes the local setting for the study, the drivers for the initiation of the Compassionate Neighbours project and introduces the researcher. Early reflections on reflexivity are included, a strand returned to again in Chapter Ten.

Chapter three: A review of the literature critically appraises the evidence relating to a new public health approach to end-of-life care and new public health approaches in general. The chapter builds the case for why this study is needed. It concludes with a statement of the problem and the articulation of the aim and research questions for the study.

Chapter Four: Research Design reflects on the requirements and restrictions set by the local context and field on the research approach. The author's paradigmatic stance is discussed and the paradigmatic assumptions made for the study are presented. The methods chosen for the study are explored and the rationale for each presented. A reflection on ethical issues and rigour conclude the chapter.

Chapter Five: Data collection describes the conduct of the study in practice. The type and nature of data collected are presented, with a description of the challenges encountered during the data collection process. Basic demographic data and

pseudonyms are presented to allow orientation to the subsequent chapters describing the findings of the study.

Chapter Six: The project in practice is the first of three results chapters. It presents data and themes relating to the actions that supported the initiation, development and integration of the project in a new space between a hospice and lay community setting.

Chapter Seven: Relationships as both process and outcome is the second of the results chapters and explores the experiences of participants and the impact of the project. Relationships are seen as the thread linking experiences of participants and are seen both as the process through which impacts are achieved whilst also understood as the impact or endpoint themselves.

Chapter Eight: Mutuality as a new basis for interaction is the final results chapter and takes a more analytical perspective. It draws out the emergence of three underlying drivers: altered power dynamics; relationships defined by reciprocity and a sense of agency developing. These three drivers inform a new basis for interaction for all parties involved in the project. This basis is one of mutuality.

Chapter Nine: Collective social capital: a new model for new public health and end-of-life care discusses the main thesis of the dissertation. Collective social capital is introduced as a new term that captures the new relationships of interdependence and mutuality that exist throughout the project, with particular relevance for the relationships between lay members of the community and organisations such as hospices.

Chapter Ten: Final reflections and recommendations summarises the key messages from the study, reviews the limitations and unanswered questions and poses a series of recommendations for research and practice. Finally, it returns to the thread of a reflexive account, started in Chapter Two and positions the results of the study in this reflexive context.

1.3 A comment on the language and style of the dissertation

The dissertation is written using the past tense. This is a considered approach. The dissertation was written after the study period ended and as such reflects on events that took place in the years preceding it. The Compassionate Neighbours project is still very much in existence and is a current, evolving and real presence. There was a temptation to write this as a contemporaneous reflection but, as this study relates

to a defined time period in the evolution of the project, the language has been chosen to reflect the historical nature of this study.

This dissertation is written in the first person. Although this represents a deviation from much academic writing, there is a recognised tradition within qualitative approaches of using this style of writing (Gilgun, 2005). My role as a participant researcher further required this approach to allow the writing to authentically and legitimately represent my views, perspectives and experiences through the project.

Finally, a note on terms used within the dissertation. Debate exists about the differing uses of the terms palliative care and end-of-life care. Palliative care is a historically older term, developed in the 1970s to describe the developing field of hospice care or holistic care originally developed by Cicely Saunders. End of life is frequently used to denote the last days or hours of life (Leadership Alliance for Dying People, 2015) but end-of-life care is also used in a wider sense to describe supports for people in the last years, days or hours that go beyond professional, or palliative care services (Kellehear, 2005). For this dissertation, palliative care will be used to describe professionally led services designed to care for people with life limiting illnesses. End-of-life care will be used in its broader sense, to describe the approaches supporting those with life limiting illnesses more generally, incorporating both professional and lay approaches. An exception will be when referencing texts, where the original usage will be preserved. End of life is a descriptive term when used in relation to care. Therefore the hyphenated version will be used in this dissertation except once again when other authors have used a different form.

Chapter Two: The context of the research

This chapter provides an introduction to the setting for the research, the impetus for the study and my role as researcher within this. The Compassionate Neighbours project is described briefly, allowing an appreciation of the basic structure of the project to inform the discussions that follow. Finally I present a reflexive introduction. These reflexive themes are returned to once again at the conclusion of the study in Chapter Ten.

2.1 Introduction to the local context for the research

The hospice in which this study was based is a large urban hospice in a major city in the UK. It provides inpatient, outpatient, community and day care for over 2000 patients per year. It is situated in a prominent geographical position within the community and is well known local institution. It receives approximately 50% of its funding from the NHS and raises the remaining through voluntary and fundraising efforts. The local areas are diverse. Joint Strategic Needs Assessments (JSNA) for the three boroughs served describe mixed ethnic and socio-demographic contexts (Association Public Health Observatories, 2008). This setting can be contextualised using three indicators: the local areas served have higher than average ethnic diversity, lower than average age profiles and higher than average hospital deaths (Public Health England, 2017).

Through two independent needs assessments, the hospice became aware that it was providing inequitable care, particularly in terms of ethnicity and non-cancer populations. This was in line with the broader concerns and recognition of many services (Ahmed, Bestall, Ahmedzai, *et al.*, 2004). There were also further reflections on the sustainability of the service currently offered, with respect to the anticipated increase in demand for palliative care services through changing patterns of illness and demographics. As one means of beginning to understand and address these differences in access to services, the hospice began a series of conversations and projects with a local community development charity. This charity had strong links with local communities, particularly within the Black, Asian and minority ethnic communities but no previous experience in end-of-life care, working previously in mental health, diabetes and weight management and maternity care. The community development charity brought public health and community

development skills that the hospice did not otherwise have access to and this was central to the hospice developing and refining new perspectives on care and support. The dialogue that developed between the two organisations lasted a number of years, during which a number of projects were worked on collaboratively and the hospice learnt to undertake work informed by community development principles. After five years of collaborative working in this way, it was decided to build on these successes and work in partnership to launch a larger project, building on the application of community development principles to end-of-life care.

2.2 My role within the hospice

I had first come to the hospice as a palliative care doctor and had spent the year prior to the study working on the wards and in the community. I had been attracted to the hospice because of its outward facing attitude and its commitment to redressing established inequities in care. I became involved in the discussions with the community development charity, in particular with regard to the type of new models that could be developed.

I had spent over a decade working with a new public health approach to end-of-life care project in the state of Kerala in southern India (Kumar, 2007). In the Neighbourhood Network in Palliative Care programme (NNPC), large numbers of community volunteers take part in training programmes and develop end-of-life care services in their local areas. They organise, fundraise and manage the services that are led by local volunteers and supported by doctors and nurses. It is based on an explicit model of empowerment; the dual aims of the programme are to develop appropriate and accessible palliative care services whilst also developing the skills, capacity and knowledge of the local community, such that they are able to take more control over issues affecting their lives beyond the remit of the programme. It has been successful both locally and internationally. It was made a WHO collaborating centre in 2010 as a model for appropriate and sustainable healthcare at the end of life (WHO, 2010).

Through working closely with this programme over a number of years, I had developed an understanding and appreciation of the role lay communities could play in end-of-life care and techniques for supporting and sustaining this involvement and had completed a masters study exploring the differing models of volunteering in

existence in end-of-life care internationally. But further to this, it had forced a profound realignment of how I understood the relative role of professionals and communities at the end of life. One statement used commonly in by the NNPC programme served to encapsulate this for me: 'chronic and life limiting diseases are social problems with medical components, rather than the commonly held converse view' (Sallnow, Kumar and Numpeli, 2010). This view has informed much of my practice over the past decade and continues to motivate me when looking for solutions for current challenges facing end-of-life care.

My reflections on the reasons for the success of the Kerala model, and the consideration of whether something similar could work in the UK formed the basis of many of the early conversations with the hospice and the community development charity. A series of funding applications were written in 2013 and 2014 and when these were successful, the community development charity and hospice devised a new project, Compassionate Neighbours. Evaluation and research were priorities for the hospice and I was appointed as a doctoral student, tasked with the broad brief of evaluating and understanding this project, in a way deemed appropriate for the setting. The pilot project and my study were started in 2014 and the full project developed in 2015. The study concluded in January 2017.

2.3 The Compassionate Neighbours Project

The Compassionate Neighbours project recruits and trains local people to become Compassionate Neighbours. Compassionate Neighbours are local people who support those nearing the end of their lives in their own homes. The project focuses on supporting people to be good neighbours rather than training them in a new role. They visit local people referred into the service at home or in another, mutually agreed location. The aim is to support those at the end of life and their families through companionship, practical support, connecting people to their communities or helping people to access services they need.

Recruitment is through a series of open days that culminate in a selection day, where participants select whether they would like to participate in the project and the project managers determine if there are any reasons they may not participate. Once enrolled in the project, participants complete a training course. This is either over four full days or over two weekends. Approximately 15 participants take part in each

training programme. The training differs significantly from the traditional hospice volunteering programme and focuses on self-reflection, network development and participants developing an understanding their potential to effect change within their community. It was developed in close collaboration with the community development charity. Topics such as safeguarding, confidentiality and boundaries are covered but in a reflective rather than didactic manner, allowing participants to reflect on what they mean for them in practice, in someone's home. At the end of the training programme, a DBS (Disclosure and Barring Service) check is carried out for all participants. The project managers and Compassionate Neighbour then jointly consider the roles most appropriate for them. For some, they are matched with people in the community immediately, but for others, a different role within the project is chosen. Not everyone begins with being matched to someone in the community; some participate in other aspects of the project and some are never matched yet remain with the project.

The project holds supportive and reflective monthly meetings for all Compassionate Neighbours. In these meetings, participants can reflect on their relationship with the person they are visiting but are also encouraged to reflect on themselves and their own personal development. These are based on a model of personal and group learning from the community development charity and are termed practice development meetings (PDM). In addition to these more formal modes of support, the project hosts a weekly coffee morning in a public space in the hospice open to all participants and the general public. These meetings allow people to come and learn about the project and for the Compassionate Neighbours to meet with each other and develop the network of peer support. Internal and external speakers come and speak about topics related to the project such as how to support someone with dementia, or can be of general relevance, such as managing fuel poverty.

The project has developed to have over 200 trained Compassionate Neighbours matched with over 90 people in the community at the time of writing and has won many prestigious national awards. It has two full time members of staff coordinating the project and although initially set up outside the traditional volunteer department, is working increasingly closely with it today.

2.4 Early reflexive considerations

In this study, I assumed the role of a participant researcher. As noted earlier in this chapter, I was a well-known proponent of new public health approaches to end-of-life care when I began the study. I had travelled to different projects around the world, presented at many national and international conferences on the subject, edited a book describing new public health approaches around the world and had helped to set up a biannual international conference series. Whilst this appears as a solid commitment to the approaches, I was aware of a series of questions or tensions within the movement that I had found hard to articulate or express. I found myself questioning the way in which the approach worked in practice, or the uncompromising way in which it was presented, as the single way forward for the field of end-of-life care. Whilst believing in the principles underlying the movement and holding a commitment to new models and ways of working, I wanted to understand the detail and granularity of the approach, beyond the theory and the rhetoric. What did these projects mean to people who participated in them as compared to those who funded them? How did they work in different contexts and when did they fail? I wanted to ask challenging questions of myself and of the field. This was important such that these approaches rooted in principles of social justice and equity and with such apparent promise and support, could be used reflectively and reflexively and not be relegated as a passing interest.

2.5 Summary of chapter

This chapter has detailed the emergence of the project and presented the setting for the study. A first reflexive account was provided to introduce and contextualise the researcher and to articulate some of the motivations for pursuing a study in this field.

Chapter Three: A review of the literature

This chapter traces the development of the fields of palliative care and public health in order to understand the context for the emergence of a new public health approach to end-of-life care. The practice and evidence base informing this new approach are critiqued, setting the context for the research questions informing this study.

3.1 The development of palliative Care

In the 1950s and 1960s a series of studies emerged describing the experiences of patients dying in hospital (Marie Curie Memorial Foundation, 1952; Townsend, 1962; Glaser and Strauss, 1965; Hinton, 1965; Reynolds and Kalish, 1974). At the same time, the impact a death could have on family members was described by Kubler-Ross (1969) and Murray Parkes (1964). Dame Cicely Saunders, working in turn as a social worker, nurse then doctor, developed her philosophy of total care of the dying whilst caring for dying patients over this same period in London. She described total, or holistic care incorporating the four dimensions of physical, social, psychological and spiritual care (Cherny, 2010). This formed the fundamental philosophy underpinning the emerging field of hospice care. These four interrelating components of a person's life and suffering, which must be considered when caring for them and their family, set the field apart from the traditional biomedical focus of medical care. The term palliative care was coined by Balfour Mount as the approach developed in Canada in the early 1970s (Wilson, Ajemian and Mount, 1978).

The WHO supported the early international development of the field, defining cancer pain as a public health issue and designing the WHO analgesic ladder as a tool to inform its management (WHO, 1990). It defined palliative care as:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

(WHO, 2012)

The World Health Assembly adopted a resolution in 2014 recommending that all

countries include palliative care in their undergraduate curricula and national health policies and to ensure access to a set of essential palliative care medicines (WHO, 2014). Others have called for access to palliative care services to be recognised as a basic human right (European Association for Palliative Care, 2013).

In the UK, the modern hospice movement has grown rapidly since St Christopher's Hospice was opened in 1967 with over 220 hospices in existence throughout the four countries. Palliative Medicine became a medical specialty in 1987 and with this followed the development of hospital and community teams. A policy framework has been developed to support the field (Department of Health, 2008, 2010, 2011), NICE guidance and quality standards have been defined (National Institute for Health and Care Excellence, 2008, 2014) and most recently a broad national partnership agreed set of ambitions for the field for 2015-2020 (National Palliative and End of Life Care Partnership, 2015). Substantial national charities developed to support this work over this period of national development, with charities such as Macmillan and Marie Curie being some of the largest in the UK (Mathew, Cowley, Bliss, *et al.*, 2003). In some ways, the development of palliative care in the UK can be considered a success story. It has spearheaded an international movement recognising the needs of the dying and the UK is regularly cited as ranking the highest for quality of death worldwide (Economist Intelligence Unit, 2015).

3.2 Tensions within the movement

Inequity and changing needs

Despite these achievements, the modern hospice movement and the field of palliative care have been subject to challenges and criticisms. Inequitable access to services and variation in the quality of care provided has been voiced for many years. Early commentators described an 'underclass' of people dying from diseases other than cancer, due to the concentration of resources on those with cancer. The historical lack of provision of palliative care services to those with non-malignant diseases was termed 'morally indefensible' (Harris, 1990; Wasson and George, 2001). The hospice movement has been described as providing deluxe dying for the few through the 'scant and scandalously choosy efforts of a patchwork of local charities' (Douglas, 1992).

These concerns continue today. Despite the widespread recognition of the need to extend high quality and appropriate palliative care services to all those in need and substantial improvements made in access to services, disparities remain (Dixon, King, Matosevic, *et al.*, 2015; Office for National Statistics, 2015b; Care Quality Commission, 2016). Inequity of provision has been highlighted over a number of years according to levels of social deprivation (Sims, Radford, Doran, *et al.*, 1997; Dixon, King, Matosevic, *et al.*, 2015), age (Addington-Hall and McCarthy, 1995; Burt and Raine, 2006), ethnicity (Koffman, Burke, Dias A, *et al.*, 2007; Dixon, King, Matosevic, *et al.*, 2015), sexuality (Bristowe, Hodson, Wee, *et al.*, 2016), having a learning disability (Tuffrey-Wijne, 2003) and factors such as homelessness (Hudson, Flemming, Shulman, *et al.*, 2016) or residing in prison (Stone, Papadopoulos and Kelly, 2012).

Changing demographics compound these disparities in access. The changes in age profiles of many countries are set to shift significantly over the next 30 years and potentially lead to changing demands due to a larger number of elderly people, smaller population of working age and increasing numbers of deaths each year (Etkind, Bone, Gomes, *et al.*, 2017). The changing pattern of disease, illness and need places new and different pressures on services. The trajectory associated with advanced cancer describes a rapid decline over a relatively short period of time. Hospices developed to support this model of care, high intensity and short duration, often as an inpatient. Conditions such as dementia, frailty or organ failure have a different trajectory (Murray, 2005). Instead this takes place over a longer time period, with support needed at different time points but at a lower intensity over many years. This presents a challenge for hospices and end-of-life services. The capacity to be present throughout all these episodes is beyond current models of end-of-life care. The issues inherent in the debates being held within palliative care, such as specialist versus generalist care and early versus late palliative care reflect the field's struggle with these issues (Temel, Greer, Muzikansky, *et al.*, 2010; Quill and Abernethy, 2013).

The threats to holistic care

Further criticisms of today's practice of palliative care relate to the provision of holistic care. Physical symptom control is a key component of care at the end of life. However, some argue that it has come to predominate over the other three domains

of care with the result that palliative care has become a clinical specialty (Kearney, 1992). Whilst some within the field have questioned whether this is in fact a problem, asserting that palliative care should only concern itself with the relief of physical symptoms (Ahmedzai, 1997), others have argued that social care is becoming further marginalised by its amalgamation with psychological care, under the term psychosocial care. Under this umbrella, social needs and care are overlooked whilst the more immediately treatable conditions of anxiety or depression take precedence (Kellehear, 1999). Further concerns have been raised as to whether physicians or other professionals within the multi-professional team are best placed or able to provide support for these issues (Steinhauser, Clipp, McNeilly, *et al.*, 2000; Fitzsimons, Mullan, Wilson, *et al.*, 2007). Furthermore, some have questioned the appropriateness of placing social and spiritual issues alongside physical or psychiatric conditions at all, as they may be unnecessarily pathologised (Randall and Downie, 2006). Issues such as loneliness, sadness or a loss of faith can be common human reactions to a life limiting illness or the loss of a close friend or relative. Randall and Downie (*ibid.*) argue that these situations are not amenable to diagnosis and treatment in the same way a physical or even some psychological problems may be. They consider that classifying them together can be damaging for both patient and professional. Further to this concern about the appropriateness of a professional response to such issues is the concern regarding the sustainability or affordability of such a professional response to death and dying.

Professionalisation of death and dying

The modern hospice movement began as a response to the over-medicalisation yet at the same time neglect of the dying. The development of palliative care as a field has led to a shift in professional and societal attitudes to those approaching the end of life. Whilst this has brought with it changes in legislation, prescribing practice relating to pain and other symptoms and policy measures increasing financial and practical support for individuals and carers, many commentators feel it has helped to unwittingly usher in a further professionalisation of death and dying. This proliferation of professional support is thought to undermine existing and longstanding social or community supports. These support structures would usually assist in caring for people in the community, support care after death and into bereavement (Kellehear, 2005). This perspective is linked to the broader narratives

of professionalisation of healthcare and of risk, fear and control in health-related matters (Illich, 1995).

Further to concerns of over-professionalisation of care, the capability of professionals in providing care at the end of life has been called into question. The public and the media response to the Liverpool Care Pathway captured the anger felt when care was deemed to be inadequate (Leadership Alliance for Dying People, 2015) and the Francis Report (Francis, 2013) described the alarming conditions in which people were being care for and dying in one NHS trust. It demonstrated the lack not only of basic standards of care but of the absence of compassion.

Returning to Cicely Saunders' early writing on her vision for holistic care, she highlighted the importance of a team approach:

'skilled symptom control, the supportive nursing, the social and pastoral work, the home care, and the mobilisation of community resources ... enable the dying person to live until he dies'

(Saunders, 1998).

Today, the multi-professional team has come to define palliative care (Haugen, Nauck and Caraceni, 2010). However, the community component has been interpreted in a more restricted manner, with volunteers now seen to represent community input. The dependence by hospices on volunteers for a range of tasks is well documented (Hoad, 1991; Mount, 1992; Burbeck, Candy, Low, *et al.*, 2014) alongside their financial dependence (Gaskin, 2003).

Roles traditionally played by volunteers in hospices today are often determined by the hospice management, designed to augment the functioning of the organisation, rather than to facilitate an involvement and partnership from the community (Sallnow, Bunnin and Richardson, 2015). This sets limits on the mobilisation of community resources and the contribution members can make. In hospitals, community involvement is limited further. A recent survey of hospital volunteers demonstrated the limited involvement and training they have in end-of-life care issues (Brighton, Koffman, Robinson, *et al.*, 2017).

A focus on the individual in isolation from their networks

Palliative care has been criticised for its focus on the individual and the family as the unit of care. The early importance placed by palliative care on the care of the individual and their family represented a departure from conventional medical care that focused solely on the patient. Recognising the importance of existing family relationships, and understanding the person in the context of these relationships and history has become a central tenet of palliative care practice. This has been further important in demonstrating the impact that death, dying and loss can have on family members and there is a growing literature describing this impact on family members or caregivers (Low, Payne and Roderick, 1999; Schneider, Murray, Banerjee, *et al.*, 1999; Corden, Sloper and Sainsbury, 2002; Aoun, Deas, Toye, *et al.*, 2015). A dying person's relationships with their direct family members may be the most significant for them. However, it can be friends, neighbours or work colleagues who are peoples' closest sources of support (Burns, Abernethy, Leblanc, *et al.*, 2011). Dispersion or strained relationships can mean that family may not best placed or able to provide the necessary support. Even if family members are present and able to provide support, the impact of an illness or death is still felt among these wider networks.

Although most holistic assessments in palliative care endeavour to capture those important to a dying person, the significance of wider community networks is often underestimated by the limited terms that assume the centrality of the traditional family. Work within the discipline of social work has recognised these shortcomings. An example includes the use of eco-grams rather than traditional genograms. Eco-grams base the assessment of a person's social context on an ecological assessment. All relationships considered by the person to have significance are included, as are the different types and direction of influence of each relationship (Hartmann, 1978). This concept has been incorporated into professional practice in end-of-life care settings in the UK (Abel, Bowra, Walter, *et al.*, 2011; Carolan, 2012). In this way, the exclusion of members of the wider community in favour of family members alone can be overcome, and a more holistic or ecological view of the individual-in-community rather than the individual-in-family can be appreciated. The contribution made by community relationships to the health and wellbeing of the dying person, their family and carers can be significant, particularly around the

social care and support (Burns, Abernethy, Leblanc, *et al.*, 2011). Many feel this is best placed to come from those from within the same community, rather than professionals (Kumar, 2007).

3.3 The future for palliative care services

The challenges facing palliative care are substantial and represent both practical and conceptual issues. The challenges described here have been discussed at a national level through reports such as *Dying for Change* (Leadbeater and Garber, 2010), the *Commission into the Future of Hospice Care* (Commission into the Future of Hospice Care, 2012) and popularised by a number of recent books (Marsh, 2014; Gawande, 2015; Kalanithi, 2016). The discussions are rich and look to a range of innovations to support and develop the field. Narratives of choice, control, participation and partnership predominate, widening the understanding of death not as a medical event but a social one. One approach gaining ground within end-of-life care is the compassionate communities movement. This draws on the participatory principles of new public health and focuses on building partnerships between communities and services, recognising the expertise and role of both. The history of new public health will now be traced, in order to allow an appreciation of the principles underpinning new public health approaches to end-of-life care.

3.4 An introduction to new public health

Public health

The term 'public health' encompasses a range of meanings: an activity, a profession, a philosophy or a movement (Macfarlane and Irwin, 2009; Varavikova, 2010). Its roots as a formal discipline can be traced to the beginning of the nineteenth century, when the process of rapid urbanisation that followed the industrial revolution forced governments to introduce measures to protect the health of their populations. Thinkers such as Chadwick (Hamlin, 1994), Virchow (Waitzkin, 2006) and Villermé (Porter, 1999) began the early collection of mortality rates for different geographical areas and observed their association with social deprivation and wealth. This early epidemiological data prompted governments to take a more active role in the health of their citizens as social conditions were recognised to influence health, mortality and productivity. The microbial revolution of the mid-twentieth century provided further scientific basis for public health. The development of the germ theory led to a

shift of focus away from the social determinants of disease, and a concentration instead on a biomedical model in which antibiotics, vaccination strategies and epidemiological perspectives took centre stage.

The emergence of new public health

By the 1970s and 1980s, the primacy of the biomedical model of health had begun to be questioned. Demographic changes and the epidemiological transition from acute, infective diseases to chronic, degenerative conditions were presenting new challenges to healthcare and public health services. Medical factors were recognised as constituting only part of the solution to maintaining health (McKeown, 1979; Szreter, 1988).

Movements outside health and medicine such as the recognition of indigenous or traditional knowledge, urban regeneration, community development, independence against colonial rule and aid for low income countries also contributed to the shift in attitudes around what was necessary to promote and sustain healthy populations. Ideas suggesting that governments and biomedicine did not possess all the answers gathered ground and alternative perspectives and possibilities began to be explored. The principles of this new perspective, or new public health, as it became to be known were first expressed by the then Canadian health minister Marc Lalonde in 1974 in the 'health field' concept (Lalonde, 1974). This argued that health could best be promoted by prevention rather than cure and emphasised the role that lifestyle factors, the environment and healthcare organisation play in maintaining health. Following this, the World Health Organisation (WHO) released the Declaration of Alma Ata (WHO-UNICEF, 1978) which positioned primary health care as participatory health care, in which people have a 'right and a duty' to participate in. Some years later, the WHO released the Ottawa Charter for Health Promotion (WHO, 1986) which defined the new field of health promotion as 'the process of enabling people to increase control over, and to improve, their health.' Further it outlined the five pillars on which health promotion was based: build healthy public policy; create supportive environments; strengthen community action; develop personal skills and reorient health services.

The new public health focused on the wider, social determinants of disease, participation, equity and social justice (Baum, 2015) and aimed to challenge the

professionally dominated public health of the previous era, by working *with* people, not *for* people. Health promotion was the early practical manifestation of this new approach. This included a wide remit and allowed the incorporation of both traditional, conservative actions such as health education and the more radical ideas of community development (Minkler, 1989). Lupton asserts that although the new public health is often represented as a break between the earlier public health endeavours, in fact, there remains a great deal of continuity between the two approaches (Lupton, 1995). Beattie (1991) goes on to describe health promotion activities as split between differing philosophies, for example: paternalism and participation; individualism and collectivism; and conservative and reformist. Some believe that this incorporation of diverse activities and ideologies under one title are in fact a strength of the Ottawa Charter (Baum, 2003) whilst others feel it represents a weakness, as no unifying theory or set of beliefs exists to underpin it (Naidoo and Wills, 2011).

In the years since the publication of the Ottawa Charter and the widespread international adoption of the principles of health promotion, some authors have cast a more critical gaze over the assumptions inherent in the document and the practice it has led to. McPhail-Bell and colleagues (2013) question the 'grand narrative' of health promotion, using critical discourse analysis to examine the context in which the Ottawa Charter emerged. They argue, from a post-colonial standpoint, that non-Westernised or indigenous views were silenced during its production and that it provided a normalised Western view of health, focusing on individualism and not representing indigenous or collective models of health and wellbeing.

The practice of new public health today

Since the formal articulation of the principles underpinning new public health in the 1970s and 1980s, there has been a variable take up of the approach. Some authors have suggested that the focus on neoliberal economic policies by many countries in the years following the Ottawa Charter and Alma Ata Declaration and the forces of globalisation emerging towards the turn of the century meant ideals of participation, equity and social justice were frequently side-lined in favour of free markets and competition (Baum, 2015, p. 105). This changing landscape has led some authors to ask what the Ottawa Charter would look like were it to be written today, and to pose a reinterpretation of some of the principles considering today's context, including

climate change and globalisation (Nutbeam, 2008). However, despite the initial slow acceptance of many of the principles of new public health, recent years have seen rapidly increasing level of interest in the field. Diverse fields such as community development, community capacity building, social capital and social ecology are now included under the umbrella term of public health, alongside health promotion, and a proliferation of practice examples, an emerging evidence base and theoretical discussions inform the growing but diverse field.

By way of example, some of the major approaches within new public health will be now be outlined, allowing an appreciation of the diversity of approaches and the emerging evidence base and policy context supporting them.

Community engagement, development and participation

The term community development was first used in the 1960s in the USA and UK to describe the efforts at urban regeneration in the post war eras (Dixon, 1989; Green and Haines, 2002) and pre-dates both the Ottawa Charter and Alma Ata Declaration. The term now incorporates both a way of working according to a set of principles but also a profession with national professional standards in many countries (Clarke, 2011). It can be defined as both a process and an outcome. As a process it is described as developing and enhancing the ability to act collectively. As an outcome it is both described as taking collective action and the result of that action for improvement in a community in any or all realms: physical, environmental, cultural, social, political, economic etc. (Phillips and Pittman, 2009). In the UK, the term community engagement has become a frequently used term when linking these principles with health in policy documents, as it focuses mainly on the improvement of services rather than development of people. Successive governments have included community engagement as a principle that supports both right and left political aims (Department of Health, 2004; Department for Culture Media and Sport, 2006; Cameron, 2010; Cabinet Office, 2014). Community engagement as a term lacks the specific series of processes or definitions of community development (Popay, 2010). Fawcett and Paine-Andrews (1993) define it as the process of working collaboratively with, and through, groups of people affiliated by geographical proximity, special interest, or similar situations in order to address issues which affect the wellbeing of those people. This definition highlights a subtle difference between community development and engagement. Whilst community

development aims to set up an independent process of empowerment or the people involved, community engagement focuses on improving a specific health or social outcome.

The wide range of processes and outputs that can be included under the terms community development, participation and engagement can lead to confusion or misuse of the terms. Conflicting goals can be advanced under the same terms (Zackus and Lysack, 1998) or they may be used as a 'cosmetic add-on' (Morgan, 2001) to improve the appearance of projects and reports without changing the substance. Much of the variation in how the terms are used and understood relates to the differential understanding of power sharing between communities and authorities. The level of power sharing determines the degree of participation. Authors have attempted to convey this diagrammatically depicting ladders, scales or spectra. Arnstein (1969) described the ladder of participation that extends from 'manipulation' through to full power sharing. The language used suggests a strong normalising view of the author, in that elements on the lower rungs are not as worthy endeavours as those higher up. This is suggested by terms such as 'tokenism' and 'manipulation' being used to describe the lower levels (Brodie, Cowling, Nissen, *et al.*, 2009). More recently, the International Association for Public Participation (International Association for Public Participation, 2014) has developed a spectrum of participation, again determined by the level of power sharing. This contains less explicit references to the 'ideal' type of participation but recognises the utility in a range of types of participation.

Other authors have questioned the central role participation plays in the new public health. Petersen and Lupton (1996) describe the 'duty to participate' and the role that new public health plays in developing ideas of citizen rights and obligations to include the duty to participate in civic life to shape policies and projects. They also highlight that not all people are free to participate to the same degree and that without recognition of this, the process of participation cannot fulfil what it is intended to. Morgan (2001) provides a definitional divide when examining models of participation. She describes utilitarian participation as when donors or funders use community resources to offset costs, to achieve certain objectives more efficiently or cheaply. This sits in contrast to empowerment models through which participants take control of an issue and are responsible for solving their own health and

development problems. In this way, participation is seen as an end in itself, rather than as the means of achieving a specific objective. Parallels can be drawn between the distinctions here and the understanding of community engagement versus community development.

The long history of community development internationally has meant there is a broad practice and evidence base to draw on. The HIV/AIDS literature has many examples of community development initiatives that have changed behaviour or experiences (Kakietek, Geberselassie, Manteuffel, *et al.*, 2013; Riehman, Kakietek, Manteuffel, *et al.*, 2013). A recent large study in the UK, incorporating a systematic review, meta-analysis and economic analysis concluded that there was solid evidence that engagement of communities in health related projects led to improved health outcomes, self-efficacy and social support, and recommended that public health initiatives should incorporate community engagement into intervention design (O'Mara-Eves, Brunton, Mcdaid, *et al.*, 2013). Again, in the UK, guidance has been published detailing the significant evidence base for the impact of community engagement in health and steps to support the integration of principles into all levels of health and social care (National Institute for Health and Care Excellence, 2008, 2014). However, by way of contrast, a large randomised control trial recently conducted of a community engagement project 'Well London' (Derges, Clow, Lynch, *et al.*, 2014) focusing on improving health behaviours and mental wellbeing and this project in deprived areas of London failed to demonstrate significance at any of its primary outcomes. This is a pattern repeated frequently within new public health or community development evaluations; traditional methods and time frames are often unable to demonstrate or capture the effect described by participants.

Social networks, cohesion and social capital

The term social capital was popularised as a term at the end of the last century by a range of authors attempting to capture that contained within relationships between individuals, communities and the state (Bourdieu, 1986; Coleman, 1988; Putnam, 1993; Lin, 2001). The recent refocusing of attention on the social determinants of health, alongside biomedical factors, has led to the term being adopted by a range of actors across different settings (Woolcock and Narayan, 2000; Zetter, Griffiths, Sigona, *et al.*, 2006). Because of this diverse usage, the concept has been further refined and classified in the literature, to allow for these multiple contexts and

meanings. Despite these attempts to drill down into the essence of social capital, some authors remain concerned that its multifaceted usage will condemn it to being an essentially contested concept such as gender or race (Szreter and Woolcock, 2004). Further they have cautioned against its uncritical use, where it is seen in only positive terms and as a universal panacea for all current public health problems (ibid).

Many of the early authors in the field of social capital framed their discussion around the level at which it was thought to operate. Bourdieu (1986) situated his discussion of social capital at the level of individual and group relationships, focusing on how privilege was transmitted between certain groups in society. Bourdieu defined social capital as:

'the aggregate of actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance and recognition – or in other words membership of a group.'
(Bourdieu, 1986)

Relationships between individuals are understood to represent the micro-level of social capital, with relationships between groups at the neighbourhood level as meso-level social capital. Putnam (1993, 1995, 2000), in contrast, looked at the interactions and relationships at the level of the state and civil society, with this understood as macro-level social capital. He defined social capital as:

'the features of social organisation, such as trust, norms, and networks that can improve the efficiency of society by facilitating coordinated actions'
(Putnam, 1993)

Further discussions regarding the concept have drawn distinctions about whether it is an individual resource or collective asset (Lin, 2001), the mechanism or process through which it influences or relates to health (Kawachi and Berkman, 2000) and whether it can move or be transmitted through communities or societies (Waverijn, Heijmans and Groenewegen, 2017). Although numerous classifications exist and continue to be debated, a generally accepted three-tier classification is described by a range of authors (Kawachi, Kim, Coutts, *et al.*, 2004; Szreter and Woolcock, 2004). They outline bonding social capital, which describes relationships between people with characteristics in common, bridging social capital, which exists across people

with different characteristics, and linking social capital, describing relationships taking place across power gradients such as between communities and institutions.

Many authors within the field of social capital have called for a more tempered and critical reading of the concept. Whilst some believe social capital to be an inherently positive attribute (Coleman, 1988), consensus now acknowledges the positive and negative sides to social capital (Portes, 1998; Fukuyama, 2000). Further to this, distinctions have been drawn regarding differential effects depending on the level at which social capital is operating. High bonded social capital leading to close-knit groups of similar people with little bridging social capital can be excluding for those outside or reinforce specific norms for those inside the networks (Berry and Welsh, 2010). Low levels of bridging social capital are thought to be associated with low levels of trust in a neighbourhood (Li, Pickles and Savage, 2005) and levels of linking social capital affect access and use of services (Woolcock and Narayan, 2000) in communities. There is also an established inverse relationship between deprivation and levels of social capital (Kawachi, Kennedy, Lochner, *et al.*, 1997; Cattell, 2001) and increasingly, calls are being made for concerted efforts to build bridging and linking social capital where they do not exist, as they are seen as potential mechanisms through which community capacity can be built and inequities can be challenged (Wakefield and Poland, 2005). Other authors have called for the power dynamics inherent in all relationships to be made explicit, and for any discussion of social capital to include a recognition of the influence of social class, gender or race in such relationships (Bourdieu, 1986; Wakefield and Poland, 2005).

The field of social networks has developed rapidly over the past ten years and has produced a range of large-scale quantitative studies. Christakis and Fowler (Christakis and Fowler, 2007, 2008) described the spread of smoking cessation and the rise of obesity in social networks in the USA through the Framingham Offspring Study over the past 32 years. They highlight the mediating role social relationships play in individual and community level outcomes such as smoking cessation or obesity. Their studies demonstrate how a decision to quit smoking is not an isolated decision, but rather it reflects choices groups of people make who are connected to each other. The likelihood of an individual becoming obese was associated with others in their network becoming obese, and the closer the relationship, the higher the likelihood of becoming obese.

Holt-Lunstad and colleagues (2010) undertook a large meta-analysis of the relationship between social relationships and mortality, seeking to understand the association suggested in smaller studies. They demonstrated a 50% increased survival for those with stronger social relationships, higher than the survival benefit conferred by many well-known public health interventions such as giving up smoking, the pneumococcal flu vaccine or reduction in obesity. What is interesting in these studies is that social capital is not mentioned. They instead refer to social relationships and social networks. There appears to be a separation in the literature between a theoretical understanding of what is happening within social networks and a practical description of their impact or associations.

Health promotion

Although the Ottawa Charter defined health promotion broadly through the five pillars, the interpretation has often been narrower in practice. Some authors assert that health promotion in some contexts has been more concerned with health education, and about telling people how to change their behaviour, than the more participatory and critical responses from other new public health fields (Lupton, 1995). The settings approach to health promotion represents a departure from these earlier incarnations. A settings approach is situated in real world contexts such as workplaces, businesses, schools and communities and focuses on the setting rather than on behavioural interventions (Baum, 2015, p. 585). A key example is the WHO Healthy Cities initiative (Ashton, Grey and Barnard, 1986). This approach acknowledges that the potential to improve health is often held by the context in which people live, rather than within personal control. Looking at what can be changed in environments, workplaces or schools allows the responsibility for health to be held across society. A number of evaluations exist for settings-based health promotion initiatives. These have often taken the form of evaluations of complex interventions or of mixed methods studies (de Leeuw and Skovgaard, 2005; Baum, Jolley, Hicks, *et al.*, 2006), and this field has helped to champion innovative and flexible methods to capture change across broad and unanticipated outcomes over long time periods.

3.5 New public health and palliative care

Many parallels are apparent in the development of new public health and palliative care over the past half-century. Both movements grew from an awareness of the limitations of the dominant models at the time. Both recognised the needs, wishes and contexts of individuals and their communities, rather than homogenous populations. Both contained a commitment to the ecological or holistic view of health and care. For these reasons, it is surprising that there has not been more sharing of concepts and practice between the two fields. Instead, the areas are often felt to be in opposition or incongruent (Kellehear, 1999; Rosenberg and Yates, 2010). The emerging field of new public health approaches to palliative or end-of-life care represents the rich contribution in both theory and practice that is observed when concepts are shared and work is undertaken collaboratively.

Over the past two decades the language of public health has been both subtly and robustly incorporated into end-of-life care discourse. The diversity of practices within both the old and new approaches to public health today is represented within the more general public health approach to end-of-life care. The WHO has stated that countries should adopt a public health approach to palliative care services, suggesting policies should be in place to support access and opioid delivery and services should be tailored to local and contextual factors (WHO, 1990). This language reflects the older traditions within public health and their focus on population level solutions. An example of the application of these public health principles to palliative care can be seen in the WHO demonstration project in Catalonia, Spain. This was developed with the explicit public health aims of integrating palliative care services into mainstream healthcare to allow for greater access, equity and understanding of needs on an epidemiological level (Gómez-Batiste, Fontanals, Roca, *et al.*, 1996; Gómez-Batiste, Porta-Sales, Pascual, *et al.*, 2007; Paz-Ruiz, Gomez-Batiste, Espinosa, *et al.*, 2009; Gómez-Batiste, Caja, Espinosa, *et al.*, 2012). Other authors describe palliative care as a public health issue (Rao, Anderson and Smith, 2002; Leon, Florez, De Lima, *et al.*, 2011). However, they use this term to denote patient or public educational initiatives or attempts to raise awareness of and access to services. Similarly, in 2007 the Journal of Public Health Policy published a series of articles in a special interest section on palliative care as a public health issue. These articles focused mainly on low income settings, looking at the need to develop professional services that can

cope with the large numbers of people requiring urgent access to pain and symptom control and of the challenges posed by the HIV/AIDS pandemic (Jagwe and Merriman, 2007; Webster, Lacey and Quine, 2007). These approaches illustrate well the application of the older approaches of public health to palliative care.

The WHO has been active in defining and advocating for the principles of new public health. However, their advice on a public health approach to palliative care has remained firmly based on traditional methods. An exception to this is the approach advocated by Dr Stjernsward, chief of the Cancer and Palliative Care Unit at the WHO from 1980 to 1996. Reflecting on the WHO public health strategy for palliative care, Stjernsward (WHO, 1990; Stjernsward, 2007) describes the five components he believes are necessary for a national public health approach to succeed, namely: appropriate policies; adequate drug availability; education of healthcare workers and the public; the implementation of palliative care services at all levels throughout the society and empowerment of the community. This final point broadens the remit of a public health approach. It suggests the incorporation of the principles of new public health alongside the more traditional objectives, and is important in moving forward with a unified understanding of the approach.

The potential for palliative care to benefit from the application of the principles of new public health has led some authors to call for their explicit incorporation. Kellehear first described the congruence of the two disciplines (Kellehear, 1999). He named the new approach 'health promoting palliative care' and described how the principles contained within the Ottawa Charter for Health Promotion (WHO, 1986) could be applied to palliative care. This would allow the development of community owned social support, public education about death, dying and loss, alliances with public health colleagues and a commitment to enhance a sense of control for those living with a life limiting illness. This thesis stimulated interest, mainly among the palliative care profession, as to how the principles underpinning new public health could be applied in practice to palliative care settings. He further refined and expanded these ideas in *Compassionate Cities* (Kellehear 2005), moving beyond the use of the term health promotion as this suggested a professionally led service response, to include wider ranging measures from policy to community action, reflecting a settings based approach. Mirroring the diversity that exists within the field of new public health, a range of examples can be seen today. These originate

from the different schools of thought in new public health. Examples based on the principles of health promotion, social capital, community development and civic responses can be seen worldwide (Kellehear and Young, 2007; Kumar, 2007; Horsfall, Noonan and Leonard, 2011; Sallnow, Kumar and Kellehear, 2013) and are discussed in the next section. Equally, there is an increasing recognition and appreciation by scholars of the relevance of both the old and new approaches of public health to palliative care (Cohen & Deliens 2012; Sallnow, Tishelman, Lindqvist *et al.* 2016, Appendix 7; Dempers & Gott 2017).

Health promoting palliative care

Kellehear's application of the principles of health promotion to palliative care has led to a series of practical examples of health promoting palliative care, particularly evident in Australia (Kellehear and Young, 2007; Kellehear and O'Connor, 2008). Health promoting palliative care was endorsed by the national body in Australia, Palliative Care Australia and in 2003 they issued guidance which advocated the inclusion of health promotion principles into palliative care practice (Palliative Care Australia, 2003).

Despite these suggestions of success, the integration of health promotion into mainstream palliative care services has not been straightforward. Rosenberg (Rosenberg, 2012) describes how many palliative workers feel they are already undertaking this work in their usual practice, or that it is an optional extra that comes second to clinical care. He feels a limiting factor in the success of this approach is an inability to demonstrate to palliative care workers that this work represents a return to the fundamental aims of palliative care or healthcare. A further limitation can stem from this, as the term health promoting palliative care places the onus firmly within the remit of palliative care services, rather than with the other services dealing with death, dying, loss or care, or in fact the wider community as described by Kellehear (2005). This narrow understanding of where the responsibility for such work may lie may limit its effectiveness and reach as it is based on wide community and intersectoral support and leadership.

Community development approaches

In the late 1990s in the southern Indian state of Kerala, a community development project was set up both to improve the palliative care services available in the state and to establish an independent process of community empowerment, such that it became an end in itself (Kumar, 2007; Sallnow, Kumar and Numpeli, 2010), as introduced in Chapter Two. Members of the community build teams that eventually become independent; delivering home based palliative care for their community through a network of volunteers, doctors, nurses and a mobilised wider community. The model, termed the Neighbourhood Network in Palliative Care (NNPC) has trained over 12,000 volunteers to date, has over 70% coverage in many areas (compared with the national average of 2%). It has been looked to as an inspiration and in 2010 it was recognised by the WHO as a collaborating centre in community participation in end-of-life care (WHO, 2010).

Despite the apparent successes of the NNPC, there remain a series of considerations with such a model. For initiatives designed on clear community development goals, the outcomes often cannot be described in advance. In the case of the NNPC, although palliative care services have developed, it now covers community development projects in community psychiatry, rehabilitation and renal replacement therapy and the language has changed from palliative care to long term care and palliative care, reflecting this more inclusive scope of concern. This is a result of the evolution of a community driven project. In the words of one community volunteer from the NNPC, 'we are trained to diagnose suffering, not diseases' (Kumar, 2008). Such a project develops to support the needs of the community who are driving it and not those within specific funding or medical parameters. Furthermore, initiatives such as the NNPC can exert significant influences on the relationships and actions of local or national governing bodies. Whilst such an influence is important to instigate lasting change, it can cause tensions both within the movement and in wider society. Due to the massive social support generated by the work of the NNPC, the Keralan Government has been forced to recognise the importance of its work and allocate funds, resources and appropriate recognition. This has led to increased government involvement in the work, something that people inside the movement believe can stifle the innovation and the community owned nature of work (Kumar, 2013). Others suggest this incorporation of the work into mainstream services is actually an aim of the initiative,

to allow services to be available for the population as a whole. They argue that the development of parallel services outside state services is at best inconvenient and at worst supporting a state withdrawal from key services (Sallnow, Kumar and Numpeli, 2010). This involvement of governments and local authorities in the work brings up questions of power and power sharing. Finally, although there appears to be immense support for the movement both from within the state and internationally, evidence of the impact of the initiative remains anecdotal.

Social capital and social network approaches

In Australia, Horsfall, Noonan and Leonard have contributed a growing body of evidence exploring the role of carers and community networks in caring for those dying at home. In one model, community mentors, trained people who have previously cared for a dying person at home, are paired with a current carer. The mentor supports the carer through the caring process by enabling them to mobilise their social support networks (Leonard, Horsfall and Noonan, 2010). The results of projects such as these suggest that the experience of the caring process for family, friends and the wider community can be a positive one, challenging the dominant view of caring being a burden and a drain on personal resources (Horsfall, Noonan and Leonard, 2011). The authors suggest that these models represent both community development and social capital generation, whilst also changing experiences of those at the end of life. This model has been adapted by a palliative care service in Devon, UK. There, the responsibility for mapping and mobilising the social network of the carer lies with a healthcare professional and volunteer (Abel, Bowra, Walter, *et al.*, 2011). This work is similar to the eco-gram described earlier (Hartmann, 1978). Whilst this may develop the social capital of the specific family or social network, Abel *et al.* (*ibid.*) accept that it does not immediately influence the wider social capital of the community.

Compassionate communities

The term compassionate communities has arisen in recent years to describe the range of different approaches that develop the role of communities in death, dying, loss and care (Kellehear, 2005). This umbrella term is understood to include both community development approaches and social network or social capital approaches but remains a loosely defined and often poorly understood concept (Paul & Sallnow 2013, Appendix 7).

Examples of practice termed compassionate communities have developed in the UK and worldwide and have often emerged through hospices or palliative care services. Hospice and palliative care services have expressed significant interest in developing these approaches (Paul & Sallnow 2013, Appendix 7) and stand as the context in which the majority of current projects are situated (Barry and Patel, 2013). The compassionate communities project set up through Severn Hospice serves as a good example of the type of projects being developed through the hospice sector currently (Cronin, 2016). The project was set up to support socially isolated and otherwise vulnerable older people. Members of the community are trained and visit people in their homes and support them socially. Although the volunteers are trained initially by the hospice, they are subsequently owned and managed by the local community. Analysis of early quantitative data on the impact of the project on health service utilisation shows that the use of GP home visits, surgery visits, telephone calls and accident and emergency attendance has reduced for all elderly people supported by the service (ibid.).

The compassionate communities project developed through the Murray Hall Community Trust represents a different approach to the more traditional hospice-initiated developments. Murray Hall is a community development charity caring for children and adults across the life course, of which palliative care service provision is one component (Patel, 2016). The principles of a non-clinical approach to end-of-life care proposed by the compassionate communities movement resonated with the model of palliative care Murray Hall had been practicing. Their development of a compassionate community approach involved the employment of a community development worker for compassionate communities, creation of Compassionate Communities Champions and an early linking with existing community efforts supporting death, dying and bereavement (ibid.). This approach involved raising awareness of the range of community action that existed already and integrating it into specific projects to further build community capacity. It is important to note that this work took place outside formal palliative care services such as hospices although worked closely with them.

Civic approaches

Moving beyond approaches based at an individual and community level, Kellehear (2016) sets a further level of intervention for new public health approaches – led by local government or local councils. He describes how such bodies have engagement in all levels of local life and therefore represent a means through which change can take place in multiple different settings. This approach is outlined in the Compassionate City Charter (ibid.). It sits apart from compassionate community initiatives through its focus on civic rather than healthcare bodies or community groups and as a result, aims to achieve a broader remit for sustainable change. Studies are being developed to understand the impact such a settings based approach can have in end-of-life care (Kellehear, 2017).

The policy context

The challenges facing hospices and end-of-life care have been widely acknowledged and a policy context has developed that is increasingly open to and supportive of new models of care. The Ambitions for end-of-life care (National Palliative and End of Life Care Partnership, 2015) contain six ambitions for the field; of which number six is 'Each community is prepared to help'. Under this heading, the first section relates to new public health approaches and compassionate and resilient communities. The Cabinet Office released a funding call in conjunction with Hospice UK in 2014 for access to a £1 million fund supporting social action at the end of life (Cabinet Office, 2014) and in the same year, Public Health England and National Council for Palliative Care developed the Pathfinders initiative, aiming to bring together and showcase best practice in new public health approaches to end-of-life care (Ali and Chapman, 2015). This is in addition to generic guidance or policy developments such as the NICE guidance for community engagement in health (National Institute for Health and Care Excellence, 2014) and the numerous policies or consultations relating to community engagement, social action, resilient communities or volunteering that come from both sides of the political divide (Department for Culture Media and Sport, 2006, 2017; Cameron, 2010). These are being supported by reports from bodies such as the Carnegie Trust who released a recent report on the importance of kindness in everyday relationships for underpinning and enabling broader social action (Carnegie Trust, 2017). These

reports and policies, although still limited in number and reach are allowing a different discourse to enter the mainstream.

3.5 An emerging evidence base

The differing models presented here and included under the broad term new public health approaches to end-of-life care can pose challenges for understanding and evaluating the field. Approaches range from initiatives to develop personal or community capacity, through to changes on a societal level. This conceptual confusion has been acknowledged in the literature and attempts have been made to bring clarity to the field by categorising approaches (Dempers and Gott, 2017) and outlining the underlying principles informing the work (Sallnow & Paul 2015, Appendix 7). A pressing requirement for the field is to understand and develop an evidence base that pertains to specific approaches within the overarching term of a new public health approach.

A systematic review was conducted by the author and colleagues during this study and the full paper can be found in Appendix 7 (Sallnow, Richardson, et al. 2016, Appendix 7). Evidence was found for a range of outcomes relating to a new public health approach, specifically relating to community action as categorised one of the pillars within the Ottawa Charter (WHO, 1986). The term community action is considered inclusive of compassionate community, community development, social network and social capital approaches and currently comprises the largest body of evidence relating to new public health approaches in end-of-life care.

This systematic review used the techniques of narrative synthesis and meta-ethnography to integrate outcomes from both qualitative and quantitative data. Three themes emerged detailing the impact community action projects could have. The first *making a practical difference* demonstrated the immediate impact such projects had on the experiences of those dying and caring. This could include reducing social isolation, improved symptom control or linking to services to provide further resources. The second theme *individual learning and personal growth* captured the changes that took place in the people caring for and supporting others. These changes were evidenced as having implications beyond the caring events, and to change attitudes and develop capacity in people that they could use in future situations. The final theme *developing community capacity* showed how such

projects can change the wider social environment, through changes in social capital or professional attitudes and could influence issues beyond end-of-life care through the development of community activists. The results from the quantitative data, although relating to a smaller set of studies, could be seen to map to these three themes. These studies show how community action projects can improve the experience of carers, the strength of community networks and the likelihood of dying at home.

Since this systematic review was published, two further studies have been published with relevance to this field and with somewhat conflicting results. They will be critiqued in order to appreciate the methodological and conceptual challenges in evaluating new public health approaches. Pesut and colleagues (2018) described a pilot of a compassionate communities initiative through a hospice in Canada. Community volunteers were trained to deliver a public health navigation role to people at the end of life. The aim of the intervention was to support older adults with a chronic illness that could reasonably lead to death within the next year to develop social capital and connections within their community. Volunteers were selected according to a set of criteria, including a year's experience as a volunteer. Although a main aim of the study was to test the feasibility of the data collection procedures, the study demonstrated outcomes for both the volunteers and clients receiving the support. Volunteers described the role as highly satisfying and enjoyed the extended time for relationship building with clients. Many remarked on the impact this work had on them personally, describing the reciprocity inherent in the relationship. Clients and families also reported high levels of satisfaction but some found the visits difficult to balance with their other commitments such as medical appointments and coping with large amounts of new information. This finding is important as it represents one of the few examples in the new public health literature relating to end-of-life care that presents the perspectives of those at the end of life, receiving the interventions. It illuminates the extent to which previous studies have focused on the experiences of volunteers and communities (Kumar, 2013) or carers (Leonard, Horsfall and Noonan, 2013) but how that those at the end of life have remained largely silent, in an approach aiming primarily to change their experiences.

A second paper published by Walshe and colleagues (Walshe, Dodd, Hill, *et al.*, 2016) reported on a wait-list randomised control trial of volunteer delivered care to

individuals in the last year of life as compared with usual care. The study found no significant differences between the intervention and the control groups according to the primary endpoints, although the data suggested a non-significant reduction in the rate of deterioration of a number of parameters such as quality of life and loneliness in the intervention as compared with the control group. This study has relevance for the field in two regards. The first is that the qualitative data regarding the study, published separately (Walshe, Payne, Perez Algorta, *et al.*, 2016) suggests the intervention improved the lives of both volunteers and those approaching the end of life but this was not captured in the quantitative study. This raises important methodological questions regarding the selection of appropriate methods to capture change from differing perspectives in new interventions.

The second and broader issue relates to the relationship between befriending services and community action projects. The study by Walshe, Dodd *et al.* (2016) included a range of different types of volunteer intervention. Some involved traditional befriending models where restrictions were placed on the development of friendships and the intervention was time limited. Others could be considered as compassionate community projects, where the aim was to develop long lasting relationships between participants and to use these to build social capital and capacity within the community. These arguably have different aims, involve different methods and interventions and achieve different outcomes. The conflation of different approaches and the use of the same outcome measures may have further contributed to the lack of efficacy demonstrated.

These issues are reflected in the broader befriending literature. Large scale, formal quantitative studies have only infrequently been able to demonstrate a positive impact of befriending, despite strong qualitative evidence or anecdotal reports. Charlesworth and colleagues (2008) conducted a randomised control trial of a befriending intervention for the carers of people living with dementia. The trial measured health-related quality of life and depression scores of the carers. The study did not achieve significance and the conclusions drawn were that befriending interventions were not effective at improving wellbeing in carers. Similarly a recent systematic review of befriending interventions (Siette, Cassidy and Priebe, 2017), defining befriending as a 'unidirectional relationship aiming to alleviate loneliness with one-to-one companionship with volunteers' and failed to show impact on the

individual outcomes such as loneliness, quality of life or wellbeing, though there was a small effect size when these were combined.

When a randomised control trial of a befriending intervention such as described by Charlesworth and colleagues (2008) concludes that befriending is not effective in improving wellbeing and a meta-analysis of social isolation as carried out by Holt-Lunstad et al. (2010) suggests a 50% mortality improvement with a social network, it is difficult to reconcile these two positions. They are, of course, asking different questions of different populations but there is something more fundamental than this. Both are trying to understand the impact of social support and networks for people, and how they may contribute to health and wellbeing in the most effective way. The limited outcomes posed by Charlesworth and colleagues (2008) may have missed some of the wider social outcomes for the carer, and by excluding the befriender, they are likely to have missed changes related to that role. It may also be that the befriending intervention used in the Charlesworth study did not support the development of social support, which may be a further reason why the study did not reach significance. The definition of befriending as a unidirectional relationship by Siette et al. (2017) prevents such relationships, on the surface, from developing into sustainable models of friendship and networks as authentic friendships have, by definition, the opportunity to develop a two-way or reciprocal relationship. This difference between befriending as an intervention and befriending as a friendship has been well characterised in the literature (Thompson, Valenti, Siette, *et al.*, 2016). Participants behind closed doors may be developing these authentic relationships, but they are not being captured in the limited outcomes prescribed for the studies.

3.6 Summary of chapter

This chapter has traced the development of palliative and end-of-life care and public health, allowing an appreciation of a number of shared characteristics and drivers for both. The alignment of the two disciplines in the field of new public health approaches to end-of-life care today incorporates a range of approaches and perspectives with an emerging practice and evidence base. Tensions are observed to occur at its interface with the related but separate fields of volunteering and befriending and the context of hospices developing such approaches is highlighted as meriting particular consideration. There exists an urgent need to develop an appropriate and insightful evidence base for this field.

3.7 Statement of the problem

Following their early development at the end of the twentieth century, new public health approaches are being revisited by health and social care practice and policy in the hope they will address contemporary challenges. End-of-life care has been part of this reflection and new public health approaches to end-of-life care now stand as an established movement within the field. Increasing practice examples, policy support and significant public and professional interest have developed to accompany and support the movement. Much has been written describing the theory of such approaches; putting forth how and why new public health approaches and end-of-life care could work together, whilst at the same time large-scale practical experiments have emerged across the world, putting this theory into practice.

Despite these numerous practice examples, extensive theoretical perspectives and policy and funding support, there remains a substantial lack of evidence and transferable knowledge within the field. Questions regarding how approaches work in practice, in which contexts and with what drivers or barriers remain unanswered. The impacts of the work remain poorly characterised, specifically understanding who such approaches impact and how. With much professional effort being invested in such approaches, these are urgent questions for the field.

This study aims to shed light on many of these questions, with a specific focus on new public health approaches being developed by healthcare organisations such as hospices. In the UK, hospices currently reflect the main setting in which compassionate community projects related to end-of-life care are being developed and there is a pressing need to understand the specific challenges that this setting presents, what processes support the development of such projects and what impacts can follow. Further to this, there is a need to understand the perspectives of all those participating in or affected by this work, to ensure subsequent research and practice builds on these lived experiences, rather than theoretical aspirations. This research endeavoured to capture experiences of those participating in the project as part of their daily lives and present them as a foundation for further study and practice.

Study aim:

To understand what impacts a compassionate communities project can have when initiated through a hospice and what specific challenges this sector presents.

Research Questions:

1. How is a compassionate community project developed from a hospice setting? What processes support the work, what tensions exist?
2. How is it experienced?
3. What impacts can follow for those involved, the organization and more widely?
4. What learning exists for the hospice sector in developing such initiatives in the future?
5. How does this learning contribute to the existing understanding of new public health approaches to end-of-life care?

Chapter Four: Research Design

This chapter reflects on the requirements the research questions make on the type and nature of methods to be used. The selection of a mixed methods approach and the rationale is presented, along with a discussion of the epistemological and ontological assumptions that inform it. Methods chosen for data collection are described and critiqued and the chosen method of analysis discussed. The ethical concerns and challenges the study raised are examined alongside the quality and credibility of the research approach.

4.1 Theoretical Perspectives

Current debates within healthcare research

It is difficult to overstate the impact of the evidence-based medicine movement when considering methodological approaches within medicine and health care today. Starting in 1996 (Sackett, Rosenberg, Gray, *et al.*, 1996), it now forms the dominant paradigm within healthcare, placing the randomised control trial at the pinnacle of the evidence hierarchy and leading a movement based on high quality, unbiased science leading to efficiency and effectiveness. This movement, whilst achieving many successes is now facing a series of critiques from both within and outside the movement. Some critiques relate to the application of the techniques of evidence-based medicine in practice, the unintended consequences such as the proliferation of guidelines and research becoming unmanageable and therefore unusable, or vested interests misappropriating and influencing trials and statistics (Greenhalgh, Howick, Maskrey, *et al.*, 2014). Other authors raise a more fundamental concern; that evidence-based medicine has become a hegemonic discourse, preventing other means of enquiry or knowledge from being taken into account and, at its worst, perpetuating the power of certain groups in society at the expense of others (Murray, Holmes, Perron, *et al.*, 2007). Evidence based medicine supports a post-positivist epistemological stance, focusing on facts and an external, knowable reality and postmodernist critiques such as that provided by Murray *et al.* (*ibid.*) find this negates personal and subjective significance in what they believe is primarily a relational world.

The author's paradigmatic stance

These broad debates within science and medicine, along side my personal experiences as a doctor and a member of society have shaped and informed my personal worldview. I appreciate the nuance that exists in the world, and particularly with the fields of health and illness. I do not believe that there is just one answer to most questions, with the context, perspectives and experiences of those asking and answering influencing this. I believe that events are experienced differently depending on who experiences them and as a result there are multiple perspectives for any event, and multiple, co-existing experiences of reality. This leads me to believe that truth is not absolute and singular and that current knowledge is at best a highly contextualised amalgamation of current and past experiences.

As a result of my worldview, constructivism represents an appropriate primary epistemological stance for this research study. This states that participants experiencing phenomena construct realities and, as such, multiple realities can co-exist (Guba and Lincoln, 2005). Constructivists assert that in order to understand a phenomenon, multiple views must be captured, to allow a whole understanding to emerge. This view is commensurate with current understandings of the evaluation of the impact of health promoting work, where experiences differ for different stakeholders, depending on their perspective, and as a result, multiple perspectives must be captured (Nutbeam, 2008). This requires a paradigmatic stance that can incorporate multiple standpoints. As a result the research study will follow a mixed methods design and will operate a pragmatic approach to the epistemology informing different methods of data collection.

Mixed methods research

An understanding of the theoretical perspectives of research, or the paradigm underpinning the work has become a central component of research today. The 'paradigm wars' pitted positivism against interpretivism and led to many citing the 'incompatibility theory' as reasons why the two paradigms exist in opposition (Sale, Lohfeld and Brazil, 2002; Guba and Lincoln, 2005). However, in recent years many authors have attempted to move past these debates into new way forward or the 'third way' of mixed methods research.

Mixed methods research has been proposed as an alternative to the dichotomous debates of the paradigm wars (Creswell and Plano Clark, 2007; Johnson, Onwuegbuzie and Turner, 2007; Tashakkori and Teddlie, 2010). It represents a new perspective for those looking at complex or multiple, related issues. The field has developed rapidly and it now stands as a major research approach, particularly within fields such as health promotion (Sale, Lohfeld and Brazil, 2002) and palliative care (Farquhar, Ewing and Booth, 2011) where interventions and outcomes are often complex, long term, interdependent and hard to define. Mixed methods research can be used to denote a variety of practice and textbooks, dedicated journals, nomenclature and quality grading systems have developed to support it (Morse, 2003). Differences can occur depending when and how methods are mixed, and whether paradigms are also mixed.

This research study will follow a mixed methods approach and will follow the commonly cited tenet that the research question should determine the methods and the associated paradigm (Quinn-Patton, 2002). This pluralist approach allows for flexibility within the research design that is essential for an exploratory study in a field in which little is known. This approach is often termed a pragmatic approach (Feilzer, 2010), or as following the 'paradigm of choices', allowing methodological appropriateness to be the driving factor rather than methodological orthodoxy (Quinn-Patton 2002). Respective paradigms, such as constructivism or positivism are honoured individually. This is distinct from the paradigm or philosophy of Pragmatism that follows from the classical pragmatists which, as a separate paradigm, has been advocated by some as suitable for mixed methods research (Tashakkori and Teddlie, 2010), replacing other paradigms. Pragmatism as a distinct paradigm or philosophy states that it is the end result or action that justifies and determines the methods and, as a result, has faced criticisms of having little theoretical to guide and support it. Datta (1997) cautions that those using Pragmatism may face issues by working without a paradigmatic anchor. Paradigms are essential to guide, inform and underpin data collection methods, analysis and interpretation; much as the research question and context determine the appropriate paradigm for the research, when following a pragmatic approach. This approach will allow the paradigm of constructivism to inform the majority of the research, with critical realism to inform the quantitative component. The key principles of both

approaches and the assumptions made by the author will be outlined in the next section.

The increasing popularity and utility of mixed methods designs has meant a range of classifications now exists. This study will follow a predominately qualitative model, with quantitative data providing a supplementary role. This is represented by the nomenclature defined by Morse (2003) as QUAL + quant. The data will both be collected and analysed concurrently, meaning this will represent an embedded mixed methods design (Creswell and Plano Clark, 2007). In this model, one data set assumes a supportive, secondary role but is included as two different types of data are required to answer different aspects of the research question.

Constructivism

Constructivism asserts that reality does not exist solely as an external, immutable, knowable reality, but rather exists as the interpretations of individuals and society (Quinn-Patton, 2002). It follows that an objective assessment of any proposition is highly problematical without an understanding of the key (and often prior) meanings that people bring to their new observations and experiences (Guba and Lincoln, 1989). This proposition is influenced by the philosophy of ontological relativism, which holds that our understanding of reality depends on our perspectives and, as such, multiple views of reality can be held at the same time by different people, and can coexist (ibid.). A belief in the subjective nature of human perception and the importance of not privileging one account over another fits well with the principles underpinning the new public health, namely parity of participation and representation and a focus on equity.

Critical Realism

Critical realism is an approach increasingly used by those wishing to answer 'how' or 'why' questions about social processes and to research such processes in the field, in the context in which they occur (Robson, 2011, p. 30). It is usually explanatory research, rather than simply testing hypotheses. Critical realists believe that although an external world exists, separate to observers, the way we perceive the world depends on our beliefs and expectations (Gray, 2014, p. 26). Bhaskar (1979) situates it relative to positivism, by describing how cause and effect are perceived through a series of mechanisms, which are influenced by context, rather

than by laws that link events absolutely. Pawson and Tilley (1997) have developed this paradigm to support an empirical or scientific evaluation approach. The acknowledgement of the influence of the observer and context on data has led some authors to draw parallels between constructivism and critical realism, as both paradigms support the view that observers in some way influence what they perceive (Madill, Jordan and Shirley, 2000; Robson, 2011, p. 32). Critical realists often follow a pragmatic approach, utilising methodological pluralism to match the methods to the context and question.

Triangulation and crystallisation

When embarking on a mixed methods study, it is important to understand what the different methods represent and how they interplay. The term triangulation originates from the traditional geographical technique of using different methods to compensate for their respective weaknesses and to therefore improve the accuracy of the findings. The use of mixed methods within interpretivist or mixed paradigms has necessitated a reframing of this understanding. Authors have described that traditional or positivist definitions of accuracy and validity do not have a place in interpretivist work, but that triangulation represents an opportunity to develop a deeper and more complex appreciation of the social world as a whole (Fielding and Fielding, 1986; Moran-Ellis, Alexander, Cronin, *et al.*, 2006). Denzin (1978) gave a broad conceptualisation of the different types of triangulation, including methods triangulation, triangulation of sources, of analysis or of theory. The utility of the term triangulation has been questioned by Guba and Lincoln (2005) who discuss the use of the alternative term of crystallisation. It is argued that this allows the multiple perspectives, complexities and the lack of one specific version of truth to be represented and a better representation of what the multiple methods are attempting to inform in interpretivist research.

4.2 Requirements of the field

There were certain elements of the context of the study that were fixed and could not be changed. The first was the development of the project, Compassionate Neighbours in line with a new public health approach to end-of-life care. This brought with it a set of assumptions and principles on which the project on a whole was based. These relate to participation, equity, partnership working and social justice. This therefore placed a series of requirements on the research approach.

Any methods selected could not run contrary to these principles or undermine them. The review of the literature pertaining to a new public health approach to end-of-life care also cautions about the application of assumed outcome measures and the exclusion of certain cohorts of participants from studies.

The second precondition was that I, as a researcher was well known to participants as both a palliative care doctor from the hospice and as a proponent and supporter of the field of new public health approaches. This could not be changed and therefore presented a second requirement on the selected research approach to recognise and accommodate this situation.

4.3 The research approach

Data Collection Methods

This study examined an evolving project in its natural context. The aim was to understand and explore this existing project and context through multiple perspectives and using open and flexible methods. To allow multiple perspectives, the study needed to include multiple options for data collection. This was important in facilitating a flexibility of methods to gain as many perspectives on the same event or events as possible, but also to include data collection methods that accessed both public and private accounts by participants, to understand both what participants felt and expressed but also how they acted and behaved. Five methods of data collection were selected to allow the study to adequately capture such perspectives. These included: interviews, focus groups, participant observation, documentary analysis and use of service logs. Each method is described below, under the two sections 'Researcher generated data' and 'Naturally occurring data'.

4.3.1 Researcher-generated data

Interviews

Interviews are a central means of data collection in social and increasingly health sciences research. The proliferation of uses for interviewing means it is important to define what shape an interview will take, what purpose it will serve and how the data will be understood and used. Interviews allow participants to share their story in their own words, reflect on experiences and provide an opportunity for the participant and interviewer to explore aspects of these experiences in detail. They differ from structured interviews used in survey research, where the aim is to gather uniform

information from each participant, focusing instead on obtaining individual and personal accounts.

Interviews as a means of data collection in social science have been subject to criticism in recent years. Atkinson and Silverman (1997) raise the issue of authenticity and question the accuracy of retrospective narratives. Others have highlighted the impact that interviewer and participant gender, ethnicity, employment status and other personal characteristics can have on the relationship developed, the information disclosed and discussed, the topics that are avoided and the role of reflexivity (Finlay, 2002; Gadd, 2004). Charmaz (2014, p. 79) asserts that interviews do not reproduce prior realities; they provide statements from a particular point of view that serve specific purposes. The data gathered from in-depth interviews are often recognised as representing new data that is co-created by the participant and interviewer, and is unique to that particular context (Holstein and Gubrium, 1997).

Finally, there are differing opinions on how the data gathered through an interview should be interpreted. In this study the data was interpreted through a constructivist lens, supporting the view that the data represents a construction of reality, co-created by the participant and the interviewer. This perspective is similar to the 'traveller' metaphor posed by Kvale (1996). He describes two opposing positions on how data is understood in interviews. The 'miner' metaphor suggests that knowledge exists already, waiting to be discovered by the interviewer. The 'traveller' metaphor suggests that the participant and interviewer embark on a journey together and a rich interplay occurs between the participant's stories and the interviewer's interpretations. New knowledge and insights are generated through the process.

A criticism that has been levelled at a constructivist use of the interview is that the new knowledge created is so dependent on the interaction between the participant and the interviewer that it has little utility outside this context. This has led to concerns about the validity and stability of interview data (Ritchie and Lewis, 2010, p. 140). However, other authors have dismissed this concern, stating that although the interview does represent a symbolic interaction, 'knowledge of the social world beyond the interaction can be obtained' (Miller and Glassner, 1997).

For the research question for this research study to be answered, it was important for the personal, experiential world of stakeholders involved in the project to be explored and interviews represented the most appropriate method to obtain this data. Notwithstanding the concerns regarding the limitations or challenges posed by interviewing, this method will form the main component of data collection.

For the purposes of this research study, an interview was taken to be a face-to-face, private conversation with a series of prompts from the interviewer from an interview schedule. The number of prompts and the order in which they were used varied from participant to participant, depending on the content being discussed, as the aim was to obtain a rich and detailed understanding of the participant's experience through exploring the content in depth, rather than obtaining a superficial understanding of a broad set range of subjects. Interviews were audio recorded and transcribed verbatim. Written field notes were made following the interview and these were included for analysis.

Whilst most interviews were single interviews, the opportunity for sequential interviews was retained, allowing a revisiting of themes and areas from the first interview to be returned to and explored in more detail or from new angles. This was an important flexibility that was built into the research design and a central component of the sampling process.

Focus groups

Focus groups are unstructured or semi-structured group interviews, where the aim is to explore a topic amongst a group through discussion. Group processes are used to help members explore their ideas in more depth, look at them from new perspectives and to generate new insights (Barbour and Kitzinger, 1999; Bowling, 2002).

Focus groups were not used as a primary data collection tool in this study, but rather near the conclusion of the data collection, to gain feedback, reflections and criticisms on the emerging themes, categories and model. This was important for a number of reasons. Firstly, it acted a means of member checking, where participants could comment on whether their views and experiences had been accurately included and represented in the model, and that no significant omissions

or misinterpretations had been made (Mays and Pope, 2000). Additionally, it represented a form of participation by participants, meaning they could hold an important role in the generation of the final output, giving a degree of co-ownership and co-authorship.

4.3.2 Naturally occurring data

Participant observation

Participant observation describes the technique where a researcher joins the group or population being studied and participates in the meetings, events and actions of that group. This allows a direct experiential view of the actions and behaviours of the group and provides the researcher with an alternative perspective to retrospective accounts of the experiences. Observation can be of a range of things including physical environment, behaviours and language, expressive movement and timings (Webb, Campbell, Schwartz, *et al.*, 1966). Participant observation also allows the capturing of behaviours that are unconscious, not recognised or not acknowledged by participants. This therefore adds a further perspective to augment and complement the private accounts gained through interviews (DeWalt and DeWalt, 2011).

In this research study, participant observation was undertaken in project steering group meetings, supervision or practice development meetings, home visits and public events. I observed mainly the behaviours, language, assumptions and actions of the group. This was augmented by the documentary analysis. I joined in with discussions when appropriate but often assumed the role of the quiet observer. This is discussed in more detail in the next chapter. Field notes were made during and after the periods of observation, to include observations on actions, behaviours and attitudes and notes of any informal conversations or clarifications undertaken.

For participant observation of public meetings, a carefully considered, balanced ethical stance was taken, supported by the ethical review committee. The purpose of observing large public meetings run by the hospice was to observe the general atmosphere, dynamics, processes of engagement, activities and behaviour. It was not the purpose to gather quotes or observations of individuals. The meetings were public, open meetings, where photographs were taken and it was understood that

the material produced would be used by the hospice as promotional material. The process of consenting all participants before the meeting was not feasible as the attendees were not known in advance and arrived at different points during the meeting. The possibility of opt-out consent was considered, with attendees receiving an information sheet and placing a sticker on their name badge if they did not wish to participate in the research. However, the risks and harms needed to be balanced with such an approach. These meetings were with members of the community who did not traditionally access the hospice and, as such, may have felt intimidated by attending such an event. The hospice hosted them in order to develop relationships and confidence within the community and the process of opt-out consent may have inhibited the attendees' participation in the meeting. In this way, the research process could have harmed the process it set out to observe. In addition to this many, often unanticipated, languages can be represented at these meetings. The practical issues involved in translating the information sheets, coupled with the inability to read written information, even in the mother tongue, of many potential participants, meant this was not a viable option.

The considered approach, reached in discussion with the ethical review committee, was to place a notice at the registration desk, stating that a researcher would be present during the meeting and that she would be observing what happens in general at the event. I was available to answer any questions during the day and I was easily identified during the event. This process was reflected on following the first observation event and no one had raised any concerns with the hospice or me following this. It was felt to be an appropriate means of continuing. A code of conduct was been drawn up to outline the researcher's role, duties and boundaries during this phase of the study (see Appendix 2).

Documentary analysis

Documentary analysis is an important method when both public and private accounts are needed of events (Kellehear, 1993). The documents used in this study represent the public face of the project (marketing and promotional materials) and the organisational perspective (training programmes and evaluations). Documents were analysed taking into account the writer and intended audience. Taken in isolation, documents can represent only a limited perspective but when analysed with other data collected, particularly the participant observation of meetings and

events, they can illuminate other perspectives. They were used to understand manifest and substantive content, not to looking for deeper meanings inherent in language and text. The documents were sampled using a theoretical sampling technique that was initiated towards the beginning of the data collection period.

Service logs

The project managers kept a record using a spreadsheet file of all participants in the study. This included data on the age, ethnicity, gender and address of Compassionate Neighbours, whether they had gained a DBS check successfully, the number of matches they had participated in and the outcome of each match. Similarly for Community Members the reason for referral and basic demographic data was captured and the number of matches and their outcomes recorded.

This data was important to capture in addition to the personal and lived experiences of participants. It afforded an overview of the project as a whole, providing a sense of the context within which these individual experiences were operating and of the broader development of the project.

4.4 Data Analysis

The approach to data analysis needed to be congruent with both the methods of data collection selected, the paradigm chosen for the research study but ultimately, it needed to facilitate the answering of the research question. This study followed a modified grounded theory approach to data analysis. Grounded theory was originally described by Glaser and Strauss (1967) and offered systematic guidelines for qualitative researchers to use, to enable them to construct abstract theories regarding social processes, based on their data. This was counter to the methodological dominance of quantitative methods at the time and presented a real alternative for researchers wishing to build theory from qualitative data. Grounded theory has undergone numerous revisions, criticisms and schisms since it was first described (Charmaz, 2005; Corbin and Strauss, 2008) but it remains an important method of data analysis today.

Modified grounded theory

For the purposes of this study, I required a technique of analysis that recognised the importance of, and could synthesize, multiple methods of data collection, a method

that supported flexibility in exploring emergent avenues of thinking and data collection and that could lead to the generation of theory. Modified grounded theory as described by Charmaz (2014), follows a constructivist perspective and was selected for its appropriateness in answering the research question set out in this study.

Charmaz (2014) situates her approach to grounded theory squarely within the interpretivist paradigm and distances herself from earlier grounded theory thinkers by stating her belief that all data and theories are constructed by those involved in the process, as opposed to Glaser and Strauss's view that theory arises separately from or is 'discovered' by researchers (Glaser and Strauss, 1967). This is congruent with the constructivist paradigm on which this research study is based. The theory that emerges from the study in Chapter Nine is acknowledged to be a representation of a series of constructions regarding what meaning and impact the project can have.

The research question required that any method of analysis would allow for new and unexpected lines of inquiry to be explored. Charmaz (2014) makes this explicit in her method, by highlighting the importance of methodological eclecticism, which is similar to the paradigm of choices described by Quinn-Patton (2002) and the pragmatic approach, followed in this research study.

A central tenet of original grounded theory (Glaser and Strauss, 1967) was that the researcher should come to the data free from existing concepts or having reviewed the existing literature. This was to allow the data to be analysed inductively and free from preconceived ideas, and to allow subsequent theory to be based only on the data. This approach has been criticised for being impractical at best and counterproductive at worst. It is particularly impractical for those undertaking research in a field or setting they are already well acquainted with, or are already published in the field. In this research study, both these situations applied to me. The approach developed by Charmaz (2014) rejects this purist stance to grounded theory and supports the use of 'sensitising concepts' (Blumer, 1954), whereby the researcher brings with them ideas and initial thoughts about what might be important, but that these are critically assessed in the light of emerging data and

concepts and that they are understood to be initial starting points, rather than restrictive notions that inhibit the data collection and theory generation.

Coding

Charmaz (2014) describes coding as the pivotal link between collecting data and developing an emergent theory, as it moves from a descriptive to an analytical space. Two types of coding are outlined: initial and focused. Initial coding refers to the process of naming each word, line or segment of data. Initial coding provides the framework or structure on which further, more detailed levels of analysis can be built upon and it allows the generation of categories and theory. Charmaz (ibid.) recommends that researchers treat initial coding as an open process, and cautions about the application of preconceived concepts or codes to the data. During initial coding, you remain open to all possible theoretical directions of the data and it is only in the later stages of focused coding that you begin to concentrate on certain directions or areas.

The constructivist underpinnings of Charmaz's (2014) approach are made clear in her description of what a code represents. She underlines the importance of language, emphasising that it is not neutral and represents a particular view or set of values. As such, during the process of coding, researchers should explore their preconceptions and use of language, as well as that of participants. Charmaz (2014, p. 116) provides specific advice regarding the terminology of initial codes and suggests they should be formed with words that reflect actions, 'gerunds' rather than topics or themes. The justification for this rests on two reasons. Firstly, it decreases the tendency to code for 'types of people' and helps to prevent codes becoming static labels for individuals. Secondly, it curbs our tendency to make theoretical leaps before appropriate levels of analysis have been made. It allows us to remain close to the data.

Focused coding refers to the next stage following initial coding. Initial codes are selected that appear frequently or are thought to have more significance than other codes and it condenses the emerging analysis from the broad base of initial coding (Charmaz, 2014, p. 138). Focused codes are often less descriptive than initial codes, bringing more conceptual understanding to the codes. Focused coding makes use of the constant comparison technique (Glaser and Strauss, 1967). This applies to

the process of comparing data with data, from within the same transcript, within different interviews or data collected from the same individual, between different descriptions of the same events by participants or from different data collected regarding the same topic. During focused coding, initial codes are compared with each other and certain questions are asked of the codes, for example; what patterns emerge when the initial codes are compared, which best account for the data and what gaps exist in the codes or data? These focused codes that account for more data and offer greater theoretical understanding then become the basis for category and subsequently theory generation.

Although described as a sequential process, the movement from initial to focused coding is not necessarily linear (Charmaz, 2014, p. 141). Gaps may be demonstrated during the constant comparison stage of focused coding and the process of initial coding may need to be returned to. They are interlinked and iterative.

Memos

Memo writing is a key component of grounded theory. It is an analytical process that allows you to reflect on your codes and initial thoughts and encourages increasing levels of abstraction (Charmaz, 2014, p. 162). Memos record the process and outcomes of constant comparison and the selection and justification for initial codes to become focused ones. They represent the basis of later theory generation. Grounded theory memos differ from the common understanding of what a memo represents in the business or other sectors. They are informal, personal notes and not for public use or publication. They should be short and free-flowing and the aim is that memo writing is a spontaneous rather than mechanical process and supports your path to theory construction (Charmaz, 2014, p. 164). For the purposes of this research study, I recorded memos as part of a methodological journal.

Categories

Glaser and Strauss (Glaser and Strauss, 1967) define a category as a conceptual element in a theory. Categories emerge from focused codes but may include a number of codes within them and operate at a higher conceptual level. They may include the relationships between codes or the patterns that exist within them. A key route from focused codes to categories is that of memo taking. Memos on focused

codes help explore them and evaluate their potential as categories. Charmaz (2014, p. 189) suggests making categories as conceptual as possible and some may reflect generic social processes as the level of abstraction increases.

Sampling and saturation

Hood (2007) describes the processes of theoretical sampling and theoretical saturation as fundamental to grounded theory studies. She asserts that this is what allows grounded theory to produce an analytical rather than a purely descriptive product. These techniques allow the variations in the data to be taken into account and to contribute to formal theory generation.

Charmaz defines theoretical sampling as the process of gathering further data that is pertinent to the emerging categories and allows refinement of the developing theory (Charmaz, 2014, p. 192). She states that this is a key difference between grounded theory and other forms of qualitative analysis. Theoretical saturation refers to the process whereby data is continually sampled to refine categories, until no new insights emerge. It differs from the more commonly held understanding of data saturation, where sampling continues, usually from the same group of participants, until no new themes emerge (Coyne, 1997; Ritchie and Lewis, 2003). Theoretical sampling applies to the specific sampling of (often new) participants to refine emerging lines of conceptual understanding. In this way it can be considered to be a more active approach than data saturation. It may take the researcher away from their initial sample and lines of data collection. The initial sampling that takes place within a grounded theory study is a starting point and is guided by the research question and the initial thoughts or sensitising concepts of the researcher. This then develops into theoretical sampling as the initial codes and the categories emerge. This requires that analysis is carried out concurrently with data collection. Theoretical sampling guides further data collection and may take the researcher in unanticipated directions.

Theory generation

The final stage in the analysis of a grounded theory research study is the generation of theory. Different definitions of theory abound but for the case of this research study, the interpretive definition of a theory is used. Charmaz (2014, p. 231) sets interpretive theory generation as an alternative to the more traditional understanding

of theory which relies on a positivist understanding of the world. She places a greater priority on understanding as opposed to explanation and asserts that interpretive theories 'aim to understand meanings and actions and how people construct them.' She recognises the subjectivity of both the participant and the researcher and that these theories incorporate multiple realities, an understanding that truth is provisional, the importance of indeterminacy and that facts and values as inextricably linked (ibid.).

Theoretical sampling, saturation and memo making are essential steps in moving from focused codes and categories to a theory. Through the final stages of theoretical sampling categories are explored and expanded, the relationships between categories are understood and the researcher's own preconceptions are examined. These final stages also involve a specific type of reasoning, abductive reasoning. Abductive reasoning has been described as facilitating the search for a new theoretical explanation to account for a surprise in data (Pierce, 1958) and Charmaz (2014, p. 200) describes it as a mode of imaginative reasoning invoked when researchers cannot account for a surprising phenomenon. It is set as distinct from inductive reasoning, as it specifically focuses on data that do not fit existing inductive interpretations and uses imagination to make connections between things that had not previously been connected (Reichertz, 2007). However, the inferences made through abductive reasoning do not stay as imaginative inferences conceived by the researcher, the data are returned to and the new theoretical inferences are examined and explored, to determine whether they have any empirical basis.

The end product of the analysis for this research study is a theory regarding the functioning of and impact of the project. The limitations inherent in reducing rich and varied experiences to abstract sets of understandings are acknowledged and are discussed in the limitations section in Chapter Ten. An early map of emerging categories was taken back to focus groups of participants for their further comments and exploration and was refined and adapted in light of these comments and built into a theory following this. It is seen as a representation of experiences and meaning and as a shared construction of the participants and the researcher.

4.5 Ethics

The topic of research in palliative care populations has been extensively discussed in the literature (Raeve, 1994; Casarett and Karlawish, 2000; Dean and McClement, 2002). Early concerns regarding vulnerability and the exclusion of dying patients and their families from research studies has largely been superseded by a more reflective and considered standpoint, where the merits of participation are weighed up against the risks of an under-researched basis for treatments, care and interventions. Notwithstanding this acceptance of the importance of research in palliative care populations, people facing the end of life present specific ethical and practical challenges that must be considered when designing and implementing a research study. Furthermore, a range of ethical issues present themselves when practitioners undertake research in their own place of work. The specific ethical issues raised by this research study are now explored in detail.

Harm to participants

The topics of support and care can be sensitive topics for participants to discuss and those of death, dying and loss even more so. Some research participants were categorised as vulnerable by virtue of their suffering with a life limiting illness, being a carer, receiving statutory care services or belonging to an ethnic or other minority group. Additionally, my role as the researcher, both as a palliative medicine doctor and an employee of the hospice could have exerted further influences on the relationship with participants, making them additionally vulnerable. During interviews, focus groups or participant observation, there was a risk that participants may become upset or distressed whilst discussing these issues, although this did not happen to a significant extent in practice. These risks were carefully considered when designing the research approach. The literature makes it clear that few perspectives from those receiving or giving support as part of a public health approach to end-of-life care have been captured and it is a pressing requirement for the field that these are understood. Additionally, there is evidence available to suggest that participation in research by those who have a life limiting illness or their carers has benefits, as perceived by the participants. These include the therapeutic benefits of telling one's story and the opportunity for this to benefit others in the future (Henderson, Addington-Hall and Hotopf, 2005; Gysels, Shipman and Higginson, 2008; Todd, Laird, Boyle, *et al.*, 2009; Koffman, Morgan, Edmonds, *et al.*, 2012). As a result, to deny vulnerable participants the opportunity to take part in this

study and to make an informed decision themselves was felt to compromise the ethical principle of justice. The potential benefits and harms were explained clearly to participants, along with their right to terminate an interview, skip questions, leave a focus group or have their data withdrawn.

The rights and wellbeing of participants were a priority at all times in this study. If a participant had become distressed during an interview or focus group, I would have supported them empathetically and found out if they need some time or would like to pause or conclude the interview/leave the focus group. If the issue was felt to be more serious or require further support this would have been offered through appropriate routes. If a Compassionate Neighbour had become distressed, permission would have been sought to contact the project manager or the leader for supervision support, to allow them to follow up the issues raised. If a carer or person with a life limiting illness had become distressed, they would have been encouraged to contact their general practitioner (GP), contact the hospice or another service as appropriate. If a member of staff at the hospice or community development charity was felt to need further support, they would have been encouraged to make use of their organisational supervision arrangements or their GP as necessary. Family members, friends and the wider social and professional community would also have been supported to consider contacting their work place supervision arrangements, GP or telephone helplines as appropriate.

At the start of an interview, I informed participants that although the information they told me was confidential, if they told me something that meant either they or someone else is at risk of being harmed, I would need to act on that and inform the relevant people. If I had become concerned that a participant or someone else was at risk of serious harm, I would have again informed them that I would need to disclose this to the relevant authority to enable help to be obtained. This would have applied to safeguarding issues of children and vulnerable adults and issues of self-harm or suicide. In practice no such concerns were raised.

Issues of intrusion

An interview, either in a person's home or in another setting, can represent a form of intrusion. Although the principle of informed consent is designed to protect participants from unwelcome intrusions, fully informed consent is often not possible

in the research context (Lavelle-Jones, Byrne, Rice, *et al.*, 1993). The possibility of fully informed consent has been further questioned in the case of interviews. Participants will not know the prompts in advance, and even if they did, people often reveal unexpected insights when they begin exploring something in detail with a researcher there to listen and prompt. Interviews can have a beguiling quality, people can reveal more than they would like and regret it later (Ritchie and Lewis, 2003, p. 68). These are risks that it is difficult to militate against. In the consent process and giving of preliminary information, these issues can be raised but it may only be during the interview process that this may be experienced.

Interviews conducted in a participant's home may also represent a form of intrusion for the participant. Other home-life processes may be on going, with other family members and friends going about their daily business and the researcher may inadvertently witness the private events of others. The home setting may also be a cause for the participant to feel awkward, if the environment is unkempt, noisy or small. These issues have been discussed outside of the palliative care research literature (Elwood and Martin, 2000) and are factors that are not easily modifiable. All participants were offered an alternative setting for the interview to take place, including a private room at the hospice, in attempt to provide a different environment to the home and some participants chose this option.

Safety of the researcher

I have been working in the field of palliative care since 2009 and have extensive experience of initiating and supporting discussions around emotional topics, signposting and supporting people to seek further help and dealing personally with hearing stories of loss, trauma and sadness. I continued to draw on these existing avenues of personal and professional support during the research study. I also had additional levels of support available at the hospice from an independent trained counsellor. I kept a research diary, along with reflections and reflexivity. All this supported a healthy and sustainable approach to this work.

Issues of personal safety were also considered for the interviews conducted at participants' homes and at other places convenient for participants. The project manager had visited all the homes I visited and a risk assessment had been carried out, as part of the routine assessment when joining the project. Any alerts regarding

the property would have been disclosed to me and if potentially dangerous, alternative plans would have been made. When I entered a home to conduct an interview, I informed a member of the project management team who had access to the address of the participant. I then contacted them to let them know I had left safely. If no call had been logged after the specified time, attempts would have been made to contact both the participant and me.

Eligibility and exclusion

This study undertook to understand the experiences of those involved in a public health approach to end-of-life care. As the project was situated in a diverse area, it involved a range of people with different ethnicities speaking different languages. Interpreters were present at all public and closed events; meaning participation for all participants was possible, without extra measures brought in for the study.

Informed consent

Informed consent is the cornerstone of ethical research and it is a manifestation of the fundamental ethical principle of autonomy (Faden, Beauchamp and King, 1986). Although a fundamental component of research, many have questioned whether it is practically attainable (Smith, 1998). Similarly, there have been calls for it to be recognised as a process rather than as a single event, and that it should be renegotiated as the research progresses (Ritchie and Lewis, 2003, p. 67).

Participants were provided with written information regarding the purpose of the research, what would be involved if they choose to participate, the potential benefits and harms, details about anonymity and confidentiality, their ability to withdraw at any time and that the decision to participate or not will not affect current or future care, along with contact details for further questions. Participants were given at least 24 hours to read the information sheet before I contacted them to answer questions, talk in more detail about the study and what it would involve and to determine whether they would like to participate, except in the case of certain meetings where the participants were not all known in advance. If the answer was positive following reading this, they completed written consent prior to any data collection.

Despite this information, time to reflect and opportunities to ask questions, the participants were not able to fully consent to participating in a process during which

they did not know what avenues of discussion or personal disclosure they would embark upon. As mentioned earlier, interviews can have a seductive quality, with participants revealing things about themselves they have never previously articulated or shared with other people (Ritchie and Lewis, 2003, p. 68). For this reason, it was important that informed consent was seen as a process, whereby participants could terminate it at any time and ask for data to be removed at a later date.

Confidentiality and anonymity

Study participants' confidentiality was maintained at all times, in accordance with Calidcott principles (Department of Health, 1997) and the Data Protection Act (HMSO, 1998). Personal data was stored in accordance with data protection practices – in a locked cupboard in a limited access fob-controlled office and in a password protected log in on a computer owned by the hospice. Personal data will be destroyed in accordance with the hospice's 'Destruction of personal identifiable data' procedures and deleted from the hard drive and server. This will be done within three months of the study concluding. All data had identifiable references to other parties removed.

The impact of being a practitioner and researcher

Undertaking research in your place of work, or as a practitioner in the field can present a range of advantages and challenges (Hamberg and Johansson, 1999; Richards and Emslie, 2000; Conneeley, 2002; Reventlow and Tulinius, 2005). Although representing specific challenges, they are a subset of the wider impact acknowledged to exist as a result of the interplay between researcher characteristics, research setting and participant characteristics.

As a palliative medicine doctor and an employee of the hospice, I was well known to many volunteers and members of staff. It was not possible to keep this fact hidden from participants and indeed, doctors undertaking research roles have reflected on their experiences and concluded that revealing professional status can potentially lead to better interviews (Reventlow and Tulinius, 2005). The same authors also reflect on the ways in which the perception of the researcher as an 'expert' can be avoided and how the power balance can be shifted in favour of the participants. They suggest reflecting on the 'position' of the researcher. The researcher is often

initially put in the position of the expert by participants, but by acknowledging the process through which this has happened and returning to the aims of the research – to explore meaning for participants, in which the researcher is not an expert, the researcher's position can be changed. This approach involving an open acknowledgement of my professional role but my re-positioning as a novice in this field was adopted in this research study. Similarly, no medical advice was being offered during the research process. I had no clinical contact with current patients and was not involved in the care of any of the participants or family members of the participants in this study. Additionally I took part in a series of training programmes relating to interviewing and focus group conduction, participant observation and qualitative methods.

Benefit of the research

This research study was designed to answer a question posed by a real-life situation. In this respect, it was anticipated that it would contribute to changing current practice and attitudes to the conceptualisation and delivery of end-of-life care, locally, nationally and potentially internationally. The limited impact of much biomedical research has been recognised (Macleod, Michie, Roberts, *et al.*, 2014) and the importance of asking 'not what works in theory but what works in practice' emphasised in palliative care research (Sleeman and Murtagh, 2014). Indeed the field of 'implementation science' is a growing one (Eccles and Mittman, 2006).

It is anticipated that this research will provide benefits locally for the participants who took part in or were affected by the research study. Evidence exists to suggest that participants find taking part in interviews therapeutic or interesting and participating in the research process in general as a rewarding experience and an opportunity to give something back (Gysels, Shipman and Higginson, 2008). Further to this, the project under evaluation is a community-based and community-led intervention and the exploration and refinement of the processes and an understanding of the impacts will have local resonance and practical implications.

Some of the lack of impact of research studies has been put down to the poor dissemination of results or negligible dissemination of results due to publication bias or pressure from funders or policy makers (Sleeman and Murtagh, 2014). This is an important consideration for researchers and every attempt will be made to

disseminate and share the results of this research study, both through professional and lay routes.

4.6 Rigour

The credibility and validity of studies is of central importance to the pursuit of research. This issue has recently gained widespread attention in the quantitative sphere of research through the concern about the limited reproducibility of the results of numerous key studies, drawing into question their validity (Open Science Collaboration, 2015). Validity has different interpretations depending on whether a qualitative or quantitative approach is being followed. Mays and Pope (1995) outlined a series of considerations for evaluating the quality and validity of qualitative studies, using concepts such as respondent validation, attention to negative cases and reflexivity to set it apart from the well known quantitative tests. Ritchie and Lewis (2003) usefully describe the difference between and relevance of internal and external validity for qualitative studies. Internal validity is concerned with whether you are 'investigating what you are claiming to be investigating' whilst external validity describes whether the concepts or themes you are generating or testing are relevant or applicable to other contexts or settings. They note the direct overlap of external validity with generalisability.

In grounded theory approaches, a range of criteria has developed to assess and evaluate the quality of a study. Charmaz (2014, p. 337) describes four such criteria. Credibility is the degree to which the study has sufficient data to support the conclusions. It asks whether the links are logical and strong, if the study achieved 'intimate familiarity' with the study setting and does the study provide enough evidence for the reader to make their own informed assessment. Originality asks if the findings give a new conceptual rendering of the data and whether they have social or theoretical significance. Resonance describes the capturing of the richness of the context and the different people or institutions that comprise it. It asks specifically if the grounded theory resonates with participants in the study or setting and whether it affords them new insights into their lives and experiences. Finally, usefulness asks about the implications of the study. Does it provide new insights into generic processes or trigger new avenues of research? These criteria formed part of the research design process and were reflected on frequently during data

collection and analysis. The extent to which the study was successful in achieving these standards is evaluated in Chapter Ten.

Central to any evaluation of the quality of a qualitative study is the understanding of the interrelationship of participant and researcher in the research process. Reflexivity, where the researcher makes clear their position, thoughts, views and motivators is a central component on which the rigour and credibility of a qualitative study is judged. All researchers come with their own preconceptions but it is essential to make these visible or explicit, to allow the researcher to demonstrate to themselves and the reader the potential interplay this may have with the study. Some preconceptions are easily accessible or recognisable whilst others may be more hidden. The use of a reflexive journal is a central component in any qualitative study and this was an important tool to make explicit my own views, perspectives and biases.

This study included a range of techniques to improve rigour. A reflexive journal was kept throughout the study period, theoretical sampling allowed exploration and clarification of themes with participants or other data sources, triangulation of participants, data types and data sources, member checking of themes and participant critiquing of results and emerging themes all allowed perspectives other than mine as the researcher's to be privileged and to contribute to the final outputs of the study. These techniques and their impact are appraised in Chapter Five and Chapter Ten respectively.

4.7 Summary of the chapter

This chapter has described the methodological considerations that underpin and inform this study. The research method chosen has been described in detail and justified and the epistemological grounding for the study outlined. The ethical issues involved in conducting such a study have been considered and efforts to mitigate any harmful impacts articulated.

Chapter 5: Data Collection

Whilst the previous chapter described the theoretical underpinnings of the study, this chapter describes the data collection and conduct of the study in practice. Sampling, recruitment, data collection and analysis are described in turn and the iterative process of theoretical sampling with concurrent analysis outlined. The challenges and issues that arose during the study are articulated with a description of attempts to manage and mitigate them. The chapter also includes an introduction to the data collected, with regard to numbers of interviews, episodes of observation, documents included, service logs used and focus groups conducted. Basic demographics are provided to allow an orientation to the data to inform the results chapters that follow.

5.1 Summary of data collected

The collection period ran from September 2014 to January 2017 and Table 5.1 gives a summary of the data collected.

Data collection method	Number of episodes
Interviews	21 interviews
Participant observation	19 events
Documentary analysis	11 documents
Service log	353 participants
Focus groups	2 focus groups

Table 5.1 Summary of data collected

As described in the previous chapter, the dominant methods of data collection were face-to-face interviews and participant observation of activities of the project. This was supplemented by documentary data, selected to provide additional perspectives on the existing collected data, service log data and finally focus groups, conducted towards the end of the data collection period. Figure 5.1 provides a flow chart to show the stages and chronology of the data collection process. It illustrates the stages of sampling, coding, emergence of categories and theory development over time and the iterative nature of both sampling and analysis.

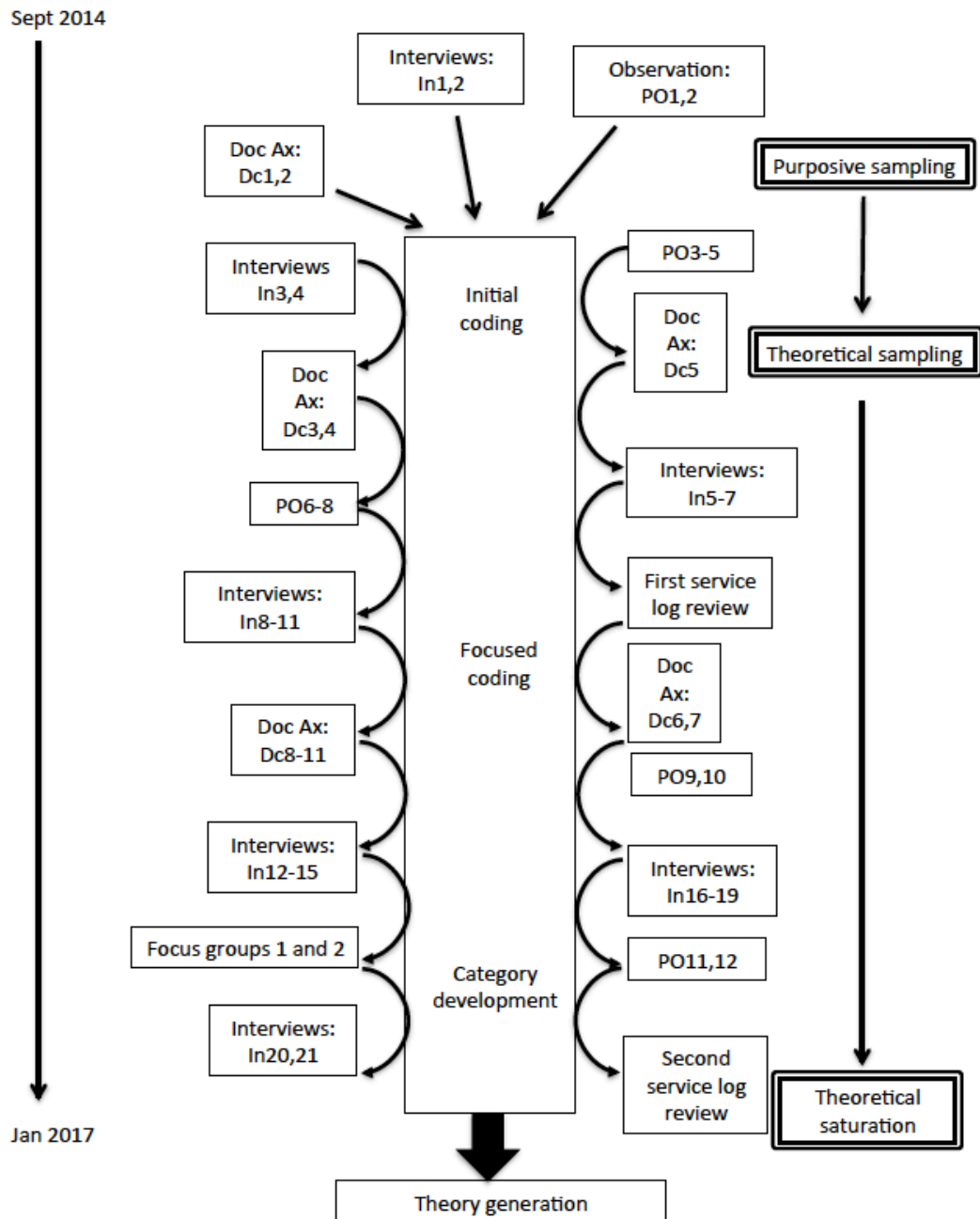


Figure 5.1 Data collection flow chart

5.2 Sampling

Initial sampling

Purposive sampling was used at the start of the study to select data sources likely to provide a rich and broad introduction to the project. Two interviews, two episodes of participant observation and three documents were included in this phase. One Compassionate Neighbour and one hospice staff member were included in these preliminary interviews. The participants were selected due to their divergent but in-depth knowledge of the project and with reference to my initial understanding of and reflection on the project, known as sensitizing concepts (Blumer, 1954). They both represented rich but different perspectives and allowed early analysis to be situated on a broad base. Similarly the two episodes of participant observation included a hospice project steering group meeting and a practice development meeting of Compassionate Neighbours. Both rich events, they again afforded a wealth of early but different codes. Three documents were selected relating to the promotional material produced for the project.

Theoretical sampling

Participants were identified through conversations with the project managers, through existing participants using the technique of snowballing and in dialogue with Compassionate Neighbours and others associated with the project. The aim initially was to develop both a broad appreciation of the range and nature of themes emerging, whilst later developing a rich and nuanced understanding of the themes emerging as central in the analysis.

Theoretical sampling builds and guides category building and is a defining feature of grounded theory approaches. Following from the very early purposive sampling to recruit the very first participants, theoretical sampling was followed for the remainder of the study (see Figure 5.1). I used theoretical sampling to determine both the next participants to include but also the type of data to collect. The different methods employed within the study were used in different sequences to illuminate and develop emerging categories.

I was guided in my sampling both by themes that appeared to have importance and relevance to participants but also to themes that I could not understand, appeared incongruent with other themes or appeared to assume a significance and weight

above their stated position within the project. The achievement of theoretical saturation and theory building are described in section 5.5.

Recruitment

Eligibility for participants

General eligibility for participation in the study included: being over 18 years of age, able to speak and read in English, or have the services of an interpreter to facilitate this, to be able to provide written consent and to have experience (direct or indirect) of the Compassionate Neighbours project.

Interviews

To recruit participants for interviews, the project manager initially approached potential participants. If the response was favourable, the project manager provided them with the participant information sheet (Appendix 2) either by post, email or in person. All potential participants had a minimum of 24 hours to read the participant information sheet. I would then contact the potential participant by phone, email or in person.

One potential participant declined to participate in the study after being approached by the project manager, on the basis they had recently participated in a different research project and had found it a difficult experience. This meant that 19/20 participants contacted by the project manager for interview participated in the final study.

Participant observation

For closed events, I approached the person convening the meeting and gave them the participant information leaflet regarding the study (Appendix 2). If they were happy for me to participate, I provided them with the participant information (Appendix 2) to circulate a number of days in advance of the meeting. I then contacted potential participants to determine if they were interested in participating. For meetings where the participants could not be determined in advance, I gave the participant information leaflets out at the start of the meeting, answered any questions participants had and obtained written consent. Participants understood that they could participate in the meeting as normal without participating in the research. At the end of the meeting I further clarified with participants that they were

still happy to participate, and made it clear they could withdraw. This was to allow for any change of mind during the period of observation, having had less time to reflect on their participation. No participants declined to participate in the study and no participants chose to withdraw during the study.

For observation of public events, a notice concerning my presence and detail about the research study was included at the registration desk (Appendix 2) and participants were given the opportunity to approach me and ask me not to include any data about themselves in the study. No participants approached me to ask to not be included in this way.

Focus groups

Participants for focus groups were selected from the wider pool of Compassionate Neighbours and staff members. No Community Members were included due to the practical difficulties in attending the venue of the focus groups. The impact this may have had on the study is discussed in a later section in this chapter. Potential participants were provided with the participant information sheet (Appendix 2) and given 24 hours to read before they were contacted by me to determine if they were interested in participating. All potential participants were interested in participating and attended the focus groups. Some participants were approached to participate who had taken part in in-depth interviews and many had not, in order to gain a wide breadth of perspectives to critique and reflect on the emerging findings.

Inclusion of documents and service log

Documents were included if they provided a perspective on an emergent theme or category. No restrictions were made on the type of documents included and therefore included a wide range encompassing poems, training material, photographs and hospice communication. No documents were inaccessible. Details of all Compassionate Neighbours and Community Members were included in the service log and the data collection period was kept open to allow this to be as complete as possible.

5.3 Participants

Interviews

Interviews were an important and significant component of data collection. Twenty-one interviews were conducted with 19 participants. Table 5.2 gives a breakdown of the participants and interviews conducted during the study. Nine interviews were conducted with seven Compassionate Neighbours, as two participants were interviewed twice. Participants were selected to participate in a second interview if the process of theoretical sampling required a further and deeper exploration of a theme from their first interview.

Type of participant	Number of participants	Number of interviews
Compassionate Neighbour	7	9 (two repeat interviews)
Community Member (including one carer)	5	4 (one joint with carer)
Hospice staff member	4	5 (one repeat interview)
External organisation staff member	3	3

Table 5.2 Overview of interviews conducted

Four interviews were conducted with Community Members. Three of these interviews were conducted with the Community Member alone. One was a joint interview with a Community Member and their family caregiver. Five interviews were conducted with hospice staff, one being a repeat interview. Three single interviews were with staff from external organisations. All staff interviews were individual. A prompt sheet was used for all interviews, from which a selection of prompts would be used. Topics were explored and probed in depth with participants and areas that were unclear clarified (see Appendix 4 for a sample interview transcript). Interviews lasted between 23 and 76 minutes, were audio recorded and transcribed and field notes were made after the interview. These were included in the data analysis. I transcribed 13 of the interviews and a medical secretary at the hospice transcribed the remaining eight. Transcripts were not returned to the participants but themes were returned to and re-explored in subsequent interviews and focus groups. One supervisor additionally read a selection of transcripts.

Table 5.3 gives an overview of the demographics of the participants in the interviews. The gender, age and ethnicity demographics are given in separate aggregates to prevent pseudo-anonymisation. Similarly the pseudonyms given later in the chapter are not linked with this demographic data.

Participant	Gender	Age/years	Ethnicity
Compassionate Neighbours	F: 6 M: 1	41 – 76	White British: 3 Asian: 1 Black Caribbean: 2 Bengali: 1
Community Members/carer	M: 2 F: 3	81 – 96	White British: 3 Black Caribbean: 2
Hospice staff	M: 1 F: 3	37 - 61	White British: 4
CD staff	F: 1	65	White British: 1
External staff	M: 2	33-38	White British: 2

Table 5.3 Demographics of interview participants

Table 5.4 lists the participants with their pseudonyms and their role within the project. The interviews are presented in the chronological order in which they took place, including the three sequential interviews.

Interview number	Participant pseudonym	Participant role
In1	Mary	Compassionate Neighbour
In2	David	Senior management team, hospice
In3	Joanna	Project management team, hospice
In4	Debbie	Senior management team, hospice
In5	Jane	Community development charity, senior management team
In6	Linda	Compassionate Neighbour
In7	Susan	Compassionate Neighbour
In8	Vicky	Project management team, hospice
In9	Mary (2 nd interview)	Compassionate Neighbour
In10	Theresa	Compassionate Neighbour
In11	Mike	Compassionate Neighbour

In12	Hannah	Community Member
In13	Will	Local council staff member
In14	Justin	Local council staff member
In15	Brian	Community Member
In16	Eileen	Community Member
In17	Laura	Compassionate Neighbour
In18	Mike (2 nd interview)	Compassionate Neighbour
In19	Sam and wife Hilda	Community Members
In20	Fathima	Compassionate Neighbour
In21	Vicky (2 nd interview)	Project management team, hospice

Table 5.4 Details of interviews conducted.

Table 5.4 details the full list of interviews conducted in the chronological order in which they took place with pseudonyms.

The final table relating to the interview data gives a context for the matches that took place within the project, allowing the relationships that developed to be understood and their discussion in the results chapters to be contextualised. To prevent inadvertent identification of participants, the ethnicities of the participants are not given. To allow the illustration of the diversity of the matches, five of the eight matches took place across differences in ethnicity.

Compassionate Neighbour	Community Member(s)
Mike	Brian
Laura	Hannah
Mary	Belinda and Hilda
Theresa	James
Fatima	Rula
Shakila	Eileen
Mark	Sam and wife Sue

Table 5.5 Matches between Compassionate Neighbours and Community Members (with pseudonyms)

Participant observation

Table 5.6 captures the range of events and the number of participants included in the participant observation, in the chronological order in which they were collected.

Participant Observation Event Number	Event	Number of participants	Setting
PO1	Project steering group meeting	6	Hospice: private room
PO2	Practice development meeting	14	Hospice: private room
PO3	Selection day	70	Community centre
PO4	Training day	15	Hospice: private room
PO5	Graduation	120 (approx.)	Hospice: public space
PO6	Home visit with CN/CM	4	Community Members home
PO7	Coffee morning	8	Hospice: public space
PO8	Coffee morning	9	Hospice: public space
PO9	Graduation	60 (approx.)	Hospice: public space
PO10	Practice development meeting	14	Community centre: private room
PO11	Coffee morning	12	Hospice: public space
PO12	Coffee morning	9	Hospice: public space
PO13	Practice development meeting	16	Hospice: private room
PO14	Coffee morning	14	Hospice: public space
PO15	Community fair	15 (approx.)	Community garden
PO16	Coffee morning	18	Hospice: public space
PO17	Practice development meeting	15	Hospice: private room
PO18	Training day	15	Hospice: private room
PO19	Practice development meeting	16	Hospice: private room
Total: 19		Total: 450 (approx.)	

Table 5.6 Summary of participant observation data

The extent to which I participated in the events varied depending on the event. I wrote notes if I could do so unobtrusively, but for most events, I wrote field notes immediately after the event. For meetings in which I had had a role in prior to the study commencement, my role was could be active, meaning I would contribute to the discussion and pose or answer questions. For other events, such as the home visit or practice development meetings, I assumed a quiet, observational role but would still participate in discussions when asked questions or was required to take part in a group activity. At times it was hard to remain in this quiet observational role, as I was drawn into discussions that centred around me and my research or my opinions on events. This occurred most often when I was observing an event in which I would not usually be a participant, meaning my presence was more obvious. An example of this is given in Chapter Seven when I describe the impact my presence had on the family of a Community Member during a home visit of a Compassionate Neighbour.

Focus groups

Two focus groups were conducted towards the end of the data collection period. They were held on two consecutive weeks for two hours. Focus group 1 had 15 participants, three male and 12 female. Focus group 2 had 16 participants with one male and 15 female participants. In both focus groups two members were members of the project management team and the remainder were Compassionate Neighbours. They were both held in a private room at the hospice. Individual data on age or ethnicity was not collected. The focus groups were audio recorded and transcribed verbatim. I placed my emerging categories on flip chart paper around the walls of the room and facilitated a discussion. At one point during the focus groups, the participants broke into smaller groups and to allow on issues and topics that had come up as themes in my results in a less open public format. Participants were invited to make notes of areas they did not want to voice publically. The notes they made on flip chart paper and sticky notes were also included for analysis and this allowed a different avenue of data collection for issues participants found it hard to raise in the group.

Service log data

This data was recorded routinely by the project management team and I extracted an anonymised copy for analysis. This happened at two points during the data

collection period. The first was half way through the study, to understand the type of perspectives it was providing, to allow its incorporation into the analysis. This data was then obtained at the end of the study period and analysed a second time in January 2017, to ensure as a complete a set of data, encompassing as many participants as possible. The final data included 180 Compassionate Neighbours, 173 Community Members referred into the project and data relating to 63 matches. The raw data was placed into basic bar graphs and pie charts to allow for its interpretation. These graphs are available in Appendix 1.

Documentary analysis

Table 5.7 lists the documents included in the order they were selected.

Document number	Document type	Source
Dc1	Promotional postcards for project	Hospice marketing team
Dc2	Hospice Strategic Direction 2012-2015	Hospice senior management team
Dc3	Boundaries of project	Project managers
Dc4	Training programme	Community development charity
Dc5	Poem	Read aloud at graduation
Dc6	Training evaluation	Project managers
Dc7	Feature article in press	Hospice marketing team
Dc8	Q+A session notes	Emailed to all staff
Dc9	Photographs of banners	Taken at public event
Dc10	Reflection by Compassionate Neighbour for internal collection of case studies	Project management team
Dc11	Internal evaluation report	Hospice senior management team

Table 5.7 Documents used in documentary analysis

Documents used in the analysis both emerged and were presented to me during the course of the study and also actively sought. All documents were made available to me by the relevant owners and all identifying information was removed.

5.4 Setting

Interviews with staff took place either in their place of work or in a private, quiet office, depending on participant choice. All Compassionate Neighbours chose to have their interviews in a private room at the hospice, although the option was available to conduct these interviews in a setting of their choice. All Community Member interviews took place at their home, as did the home visit. Participant observation episodes ranged from private rooms within the hospice for closed meetings, an open space in the hospice reception area for coffee mornings, public spaces for graduations and in a community garden for the community event. The two focus groups took place in a large private room in the hospice.

5.5 Analysis

Data analysis was carried out concurrently with data collection and sampling. The software tool used to input, store and organise the data was online platform Dedoose (Dedoose, 2017). This allowed coding, linking and memoing with the data. Initial coding was carried out using line-by-line coding and generated a large number of individual codes. As this stage of coding developed, certain themes could be seen to link sets of initial codes, and some codes were repeated frequently or given particular emphasis by participants. I began to explore these groups of themes, taking care not to ignore other lines of enquiry, but to begin to understand what place they had in the analysis.

Focused coding then involved the combining of initial themes into groups that shared an underlying meaning or concept and began to condense the wide spread of initial codes. Throughout this process I wrote extensive memos, detailing the importance and relevance of themes, the codes or concepts that I could not quite understand, or those that had relevance, interest or ambivalence to the rest of the data. This process was not linear. I would return to a period of initial coding when theoretical sampling produced new data to understand, or when focused coding was understood to have produced a new concept, rather than an amalgamation of initial codes. I would then return to understand the granularity of the concept first before building it up into higher levels of abstraction.

Once initial and focused coding was broadly completed, I had 149 initial codes with 56 focused codes. Again, memoing formed an important step in data analysis at this point. I began to explore relationships between codes and attempted to get at the underlying processes informing or shaping them. In order to do this I introduced a graphical means of memoing, allowing me to illustrate relationships, interfaces and groupings. The technique of constant comparison was also used at this time. In this I compared the same events at different times with the same participant and the same event across different participants or data sources. From this, categories began to emerge. I continued theoretical sampling throughout this stage, as Figure 5.1 illustrates, as new insights or relationships continued to emerge. As I refined my categories and my sampling introduced no further properties of my categories, I felt I was ready to take these categories to the two focus groups. These categories were presented to the participants of the focus groups and further refined and critiqued. I undertook two further interviews after this, to finally explore themes raised in the focus groups. These interviews helped answer and clarify the final remaining questions and I was satisfied that the categories were sufficiently explored, explicated and interlinked that they had reached theoretical saturation. I then concluded data collection and turned to raising the level of abstraction of my categories to support the building of a theory. At this point, the wider theoretical literature was turned to.

5.6 Challenges during the data collection process

The study design presented consideration and debate within the ethical review committee with regard to some aspects of participant observation and consent. The need to support written informed consent at all times was understood to conflict or potentially inhibit the open nature of the participatory project being developed. This was seen in the need to gain written consent for all episodes of participant observation, including observation of large public events, but the technique of obtaining it through opt out means such as wearing a sticker on a name badge could intimidate participants new to the hospice and inhibit their participation in the event; the main objective of the project. The ethical review committee felt that it was important the research process did not interfere with the running and conduct of the project, a view to which I fully subscribed. For this reason they suggested the method adopted in this study, of placing a note stating that a researcher would be present at the registration desk and me to be present and visible for people to

approach me individually. They asked that I reviewed this approach and reflected on its role as the study progressed. I did this both in my research diary and with my supervisors and the project management team. All agreed that this was an appropriate balance between intrusion and consent and it continued to be used throughout the study period.

Recruitment and sampling were relatively straightforward. People were keen to participate in the study as it had a positive and public profile within the project and hospice. Only one participant approached to participate declined to do so. This was due to their participation in another study being conducted in the hospice that had involved the completion of long survey tools and did not feel she had time to participate in further research studies. One drawback of the interest in participation in the study was that I had to manage this interest against the need to sample theoretically, in line with the development of my emerging categories. This led to some awkward conversations with people, as I declined to interview those asking to participate, in favour of those more reluctant, as they were able to provide me with the relevant data.

Another challenge was the large amount of data that I generated through the study period. The management of this was helped by the concurrent analysis, the initial and focused codes allowing the data to be condensed to relevant themes. However, the large number of themes during the first part of the study required use both of the online software management tool and large graphical displays along the walls of my office. The development of both narrative and graphical elements to my analysis and data management assisted in the refinement of the data.

The name of the project 'Compassionate Neighbours' was retained in the write up of the dissertation although all other identifiable names and characteristics have been anonymised. This is a considered position. The term Compassionate Neighbours is a term being used in multiple settings currently to describe compassionate community projects. The terms Compassionate Neighbour and Community Member, denoting those referred in to the project were so entwined with the interpretation of the study results and the functioning and positioning of the project as a whole, that to use different terms would have compromised the understanding afforded through the study. As a result of this, and in order to prevent pseudo-anonymisation where

participants are identifiable despite pseudonyms, some demographic data such as gender, age or ethnicity has been presented in aggregate form only.

5.7 Credibility of the research process

This study employed a range of techniques to support the credibility of the study and Appendix 6 includes a COREQ checklist of reporting for qualitative studies (Tong, Sainsbury and Craig, 2007). A reflexive journal was kept for the duration of the study, and themes from this were regularly discussed in supervision meetings, or if relating to emerging themes, explored in analysis and sampling. Participants were involved at multiple points throughout the study, not just during individual episodes of data collection. Member checking of themes was not carried out after analysis of individual transcripts but rather collectively and was related less to assessing the accuracy of the transcript and more to the relevance of the themes. During theoretical sampling, these early themes were described to participants and their views both on the themes and on where perspectives relating to them were noted and used in the data analysis. The focus groups represented a formal aspect to this process of member checking, with participant feedback, discussions and critiques helping shape the final conceptual model.

5.8 Summary of the chapter

This chapter has detailed the data collection process and given an initial overview of the data collected and demographic information. The context of recruitment, sampling, participants, setting and analysis have been presented to allow the reader an appreciation of the techniques and processes used, to support assessments of quality and validity.

Chapter 6: The project in practice

This chapter is the first of three chapters presenting the findings of the study. It explores the series of actions through which the project was observed to function. These actions encapsulate the work of the project, its boundaries, the interface with the wider hospice and wider community, how the internal rules of the project were defined and enforced and how the needs of those participating in it were understood and responded to. In so doing, this section answers the research question that asked how a compassionate community project can develop within a hospice context, and the further questions about the processes that best support, and the tensions within such a development.

Six actions emerged from the data as vital to the initiation and growth of the project. These comprised subthemes and were identified as:

1. Common causes act to unite diverse motivations
2. Training develops new relationships not roles
3. Boundaries are fixed yet permeable
4. Participants act with autonomy
5. A desire exists for control alongside companionship
6. Formal regulations are enacted alongside fluid processes

6.1 Action One: Common causes act to unite diverse motivations

This process, through which a diversity of pre-existing community aspirations and experiences of caring were brought together as a basis for working collectively, served as a unifying foundation for the project.

There are three components to this theme. The first relates to the expression of compassion. Participants drawn from a variety of local communities articulated clearly that they understood the principles of compassion and community action that underpinned the project, and many described how they were undertaking this work already, and independently.

"She [outreach worker] said 'I got people... talking about compassion.' They [people in the community centre] said 'Yes, we already do this. When can we join in?'"

(IN5: Jane, staff member at community development charity)

Even so, diversity existed between members in their rationale for the expression of compassion within a community, and their motivations for participating in the project. Individual motivations for participation included religious beliefs, personal experiences of care, a wish to feel more connected to the local community, a belief that this should happen in society, or a kind of social insurance, of wanting such a project to be available to them, should they need it in the future. By way of example Fathima ascribes her interest to her religious beliefs:

"So I'm Muslim and in Islam, the first thing you get taught is to have morals, be straight, give respect to everyone... to respect your neighbours."

(IN20: Fathima, Compassionate Neighbour)

By comparison, Theresa is motivated by a belief that a gap exists in society that should be plugged:

"I'm very, very keen for everyone in Compassionate Neighbours to feel that this is very ordinary, ordinary, it should happen in society and it doesn't."

(IN10: Theresa, Compassionate Neighbour)

Regardless of differing motivations to become part of the project, the data confirms that those engaged shared an aspiration and commitment to developing it. The support of the project by local communities was evident; I observed long waiting lists throughout the study period for both enrolment on the training courses and referrals, and open days were full. Compassionate Neighbours took the project into their networks and those attending new training courses were often contacts of those trained in previous cohorts. This strong sense of a common purpose was noted to exist despite differences between the participants, as Mary, one of the Compassionate Neighbours noted:

"... there is such a diversity, but within that diversity there is unity, because all the different backgrounds, all the different ages, people's belief system or non-belief system, they come together in a way which is quite unique"

(IN9: Mary, Compassionate Neighbour)

Data from the service log demonstrates the diversity of the cohort according to age, gender and ethnicity. Although the gender split was 16% male and 84% female, the spread of ages and ethnicities was very broad (See Graphs 1-3, Appendix 1).

Despite this endorsement of the project and the principles underpinning it, there were some reservations expressed in an early meeting. This related to the possibility of withdrawal of healthcare services as this project developed. Compassionate Neighbours in the selection day (PO3) asked whether the project was a means of providing less services to people, saving money asking them instead to just care for themselves.

The frequent references to grief, loss and bereavement across the cohort of Compassionate Neighbours pointed to the unifying nature of these shared, universal experiences. This was the second component within this theme. Many of the losses discussed focused on participants' mothers. Compassionate Neighbours spoke about the need to make sense of the loss of their mothers, of experiences of caring for them as they died and of the ambivalent relationships many had had with them.

"We thought ... one of the things we are doing was sort of resolving losses we've had, like the death of our mums."
(Compassionate Neighbour, Focus Group 2)

The final component within this theme relates to the unifying nature of collective action. There was something inherent in the joint cause, of working together to achieve something bigger that served as a motivating and reinforcing factor, at some points seemingly separate to the actual work and focus of the project. The unifying belief in the project succeeding was commonplace:

"... we have to have that belief that the programme is going to work and I believe that we do have that belief, and that is why we are all here."
(Compassionate Neighbour - Focus Group 2)

Such effort is both emergent and deliberative in approach:

"Where we are today. It's not just about us in this one room; its about a whole... its about bringing together the whole group and ensuring that we are all looking at the same page, and that we have the same goals, to make it successful and I can see that is where we are today."
(Compassionate Neighbour - Focus Group 2)

This core belief in the project and its success led to a series of behaviours protecting the essence of the project as this field note observing a practice development meeting illustrates:

"I observed how a core set of behaviours emerged with the first training cohort and was protected and enforced in the wider community of Compassionate Neighbours, specifically by the longer-serving Compassionate Neighbours. A specific focus was on how the group interacted as a whole, for example during Practice Development Meetings. During these meetings, participants would share personal stories of loss or suffering and the aim of the group was to 'hold the space', a term used by a facilitator in the first training cohort. This involved not offering platitudes or interrupting to share your own perspectives on the story, but instead to keep the silence for some time and then to reflect with the person sharing in their own time. It was a respectful attitude and appeared to encourage people to share highly personal experiences with the group. Although this practice of 'holding the space' was based on the principle of respect, the means in which this was enforced could be blunt. I observed one meeting when a new Compassionate Neighbour tried to interrupt a story someone else was sharing about a recent personal bereavement, to offer condolences and say they were sorry. A longer serving Compassionate Neighbour, from the first cohort, immediately shouted 'Shhh!' to the newer Compassionate Neighbour, leading to embarrassment for her in front of the group. From this I understood that the community of Compassionate Neighbours and the code of attitudes and practice on which it has been created assumes a greater relevance than individuals or individual relationships comprising that group."
(PO13: Practice development meeting)

During my observations of public meetings, I came to appreciate the role the diversity of participants on the training cohorts played in the overall experience. One Compassionate Neighbour remarked at a graduation event:

"It looked so odd [such a diverse group of people together], I wondered how we would all relate."
(PO9: Graduation)

He went on to say:

"soon people I would not have normally spoken to I was speaking to... the atmosphere was so warm. Being able to meet people struggling in different circumstances was important"
(PO9: Graduation)

This illustrates that not only did the Compassionate Neighbours project allow for and incorporate diverse experiences, motivations and backgrounds that participants

brought, more than this, the diversity acted to enrich the experience for participants and provide new perspectives on the lives of others.

6.2 Action Two: Training develops new relationships not roles

The data demonstrated how the training for Compassionate Neighbours enabled them to first explore and develop authentic relationships within the group before building them with those they were matched with in the community. There was an understanding by both participants and training facilitators that this was of a different nature to other types of volunteering or hospice training that may have taken place before.

The first component of this theme relates to the training as a focus on the self. Training to become a Compassionate Neighbour was based on group work with the same cohort of people organised over a series of four full day/evening meetings held on weekdays, evenings or weekends. The course was designed to be participatory, self-reflective and based group learning rather than being given answers by the facilitators (Dc4: Training agenda and PO4: Training day). The aim of the training was not to create a group of individuals that had learnt a new role and could deliver a specific, intervention, but rather to understand where participants each were starting from, to support them in the expression of their needs or vulnerabilities, then using the group as a resource, to meet those needs, such that they would be able to participate in the project as themselves and not as someone adopting a new role.

"I think it [the training] builds human beings who are capable of compassion, you know, real compassion and love, and who know what their own needs are, into the bargain, so they are part of the picture."

(IN5: Jane, staff member at community development charity)

The focus on the self within the training was something Compassionate Neighbours found different to training they had undertaken before and described how this had led to personal growth and change.

"It afforded me the time and space to look at things differently, beginning with myself."

(IN1: Mary, Compassionate Neighbour)

The second component shows the training acted as a collective venture. The sharing of personal stories and reflections, alongside exploring issues such as loss, caring and suffering facilitated these new and close bonds between within group.

"We cry, we're happy, we laugh, we talk, we share, share everything... everyone seems to be honest, they talk about their lives."

(IN:11 Mike, Compassionate Neighbour)

The third component in this theme relates to how relationships developed within training acted as a resource to draw on when in need in the future, when Compassionate Neighbours were matched up in the community, or as they struggled with issues in their own lives. Mary reflects on the life events the Compassionate Neighbours went through whilst participating in the project.

"Our lives changed in different ways ... [a] lot of us needed the offering ourselves, the compassion."

(IN9: Mary, Compassionate Neighbour)

The project manager described several situations in which Compassionate Neighbours had become unwell, been bereaved or had become carers, and how the wider group had taken up supportive roles involving accompanying them to appointments or visiting them at home. Indeed, one Compassionate Neighbour described how she had joined the project for this very reason. She was elderly and admitted to being socially isolated, and in joining had in effect created her own community around her, with a network of six other Compassionate Neighbours – with whom she undertook specific activities with and on whom she now relied on for help in a variety of matters. When she suffered a personal bereavement some time into the study period, this network provided support to her. In this sense, the Compassionate Neighbours could be understood to gain something tangible through training; the membership of a group or network of supportive peers who are able to care for one another quite separately to and independently of the other activities of being matched with people in the community. The training could be seen to stand as an activity in its own right, distinct from any matching that might follow – offering diverse groups of local people an opportunity to come together with a common purpose. Although this common purpose was ostensibly to express compassion and to care for those at the end of life in their communities, the first outcome was the expression of compassion to each other.

Graph 4 (Appendix 1) looks at the rate of completion of DBS paper work for participants on the course, with an approximate 50:50 split (51% participants undertook DBS paperwork as compared with 49% who did not). Whilst those who did not complete the DBS process were not formally interviewed, their perspectives were still sought out. Some participants who did not complete the process still attended the open coffee mornings and shared their perspectives there. During one coffee morning that I observed, a participant who had completed the training but not the DBS explained how intimidating it can be, when many people are suspicious of state offices and are reluctant to provide documents to them for fear of having benefits cut. Others explained that some people do not have the relevant documentation and are worried about this being highlighted to the authorities (PO14: Coffee morning). Developing this theme, I met a Compassionate Neighbour who had wanted to participate in the programme but had no evidence of her address or signature. As she was unable to even register for the DBS process, the hospice paid for her to obtain a set of identification at the local police station using her fingerprints. This then allowed her to begin gaining other documents that supported her wider engagement in the community (PO8: coffee morning).

Finally, Compassionate Neighbours demonstrated how they took the experiences and learning from being part of the network of supportive relationships in training, into the relationship with their Community Member with whom they were matched. In other words, the training allowed modelling of compassionate and authentic long-term relationships between people who appeared different according to a range of characteristics. These were then re-enacted with those they were matched with. Compassionate Neighbours spoke about how carefully they respected the autonomy of the person they were visiting and how they modelled these relationships in training, meaning they were better able to embody them in practice. This set an important basis on which these relationships would be built.

Joycelyn [Community Member being visited in a care home] had had a career as a chef and we talked about food quite a lot... The care home manager told me she loved ice-cream so sometimes I took her small pots... On one occasion she was struggling to feed herself, which was quite a challenge for me because my awareness of her fragility and vulnerability raised an instinct in me to assist her that conflicted with my instinct to respect and protect her dignity by not denying her this small autonomy. But I remembered a mantra from my Compassionate Neighbour training: if this was a neighbour what would you do? So I asked her if she'd like me to help and she said yes.

(Dc10: Reflection by Compassionate Neighbour for internal collection of case studies)

6.3 Action Three: Boundaries are fixed yet permeable

The boundaries for the project exhibited marked differences depending on whether they were located within or around the project.

The first component of this theme captures the nature of boundaries within the project. These were seen as fluid. Participants in the project (Compassionate Neighbours and Community Members) were not split into recipients and providers, but instead, efforts were made to ensure all were seen as people, rather than volunteers, patients or professionals. This supported a sense of being peers, which in turn influenced the nature of the relationships formed. This is encapsulated in my observation of discussions between some of the first Compassionate Neighbours as they attempted to find a word to describe those referred into the service.

The group agreed that the most important first topic to discuss was what those referred into the service would be called. There were some very strong reactions to 'beneficiaries, service user, client and recipient', people said they were derogatory. Service user was thought to be particularly inappropriate, as they were not accessing a service. After some discussion, the group decided that 'community member' was the most appropriate term, as the people being helped would be a range of people locally suffering with illnesses and also family members, who would not necessarily be patients or even known to health services. The group felt that the two terms, Compassionate Neighbour and Community Member were the best to describe what was happening in the project, even though they were quite cumbersome names.

(PO2: Practice development meeting)

During the study period, transitions occurred across these fluid boundaries. Three people who were hospice patients participated in the training and became Compassionate Neighbours, whilst other Compassionate Neighbours became unwell or carers and began to receive a Compassionate Neighbour in their homes. The lack of distinction between provider of care and recipient meant participants could traverse tradition roles and be simultaneously supporting someone in the community whilst also being a patient and receiving care at the hospice. Such blurring of boundaries and the resisting of labelling individuals with one role meant the participants could continue in their role long term; the project became perceived as a part of people's lives regardless of what else was happening. Compassionate

Neighbours were not restricted to just giving care, they were able to behave reciprocally, drawing on the support of the group and the people they were visiting, whilst also at the same time caring for others. This enabled expression of reciprocity further supporting the view that Compassionate Neighbours and Community Members were peers, at different points on life's journey. Compassionate Neighbours clearly articulated this understanding to me, one using the metaphor of being different sides of the same door.

"I'm on this side of the door today and we don't know when the exchange is gonna [sic] take place"

(IN1: Mary, Compassionate Neighbour)

Although Compassionate Neighbours enjoyed a fluidity of role and the ability to draw on support whilst actively supporting others, the role Community Members played appeared in contrast. They did not have the same opportunities to draw on broader networks of support through the project and their role did not immediately offer options to engage in the support of others. This contrast is explored further in Action 5: A desire exists for control alongside companionship.

The second component of this theme describes the fixed and impermeable boundaries between the project and the rest of the project. The reasons given by the project manager for this stance was to prevent potential professionalisation of the Compassionate Neighbours.

The project had been initiated as separate from the traditional hospice volunteering cohort from the outset, in order to emphasise a distinction in approach and the project managers described how a key component of their role was to explain and protect this difference. The difference stemmed from the identities of the Compassionate Neighbours not as hospice volunteers but as members of the local lay community and therefore first and foremost, with a different focus and responsibility to everyone else working within the hospice. The project manager describes how they were, in some respects, the focus of her work as an end in itself, compared with other hospice volunteers whose efforts would have been considered in relation to the organisation or its users as an end point:

"I feel radical ... I feel like at the end of the day, my main focus is the [Compassionate Neighbours] not the patient and that's a radical difference ... in terms of other hospice staff."
(IN8: Vicky, project manager)

An example of this was when the hospice requested Compassionate Neighbours complete the statutory and mandatory training workbook required of all staff and volunteers. This created significant conflict between the project and the volunteering department. The reasons the project managers refused to comply with this were twofold. Firstly the project managers saw these requirements as potentially excluding a large proportion of the Compassionate Neighbours due to the requirement to complete workbooks in written English and this was not in keeping with the broad principle of inclusion that the project was based on. Secondly, there was a concern that through participating in the formal hospice training, the Compassionate Neighbours may lose their self-perception as lay community members and become subtly professionalised, modifying their behaviour to act as to hospice professionals whilst out in the community.

Interestingly, whilst managers of the project sought to reinforce a distinction between the operation of the project and that of the hospice, the Compassionate Neighbours sought to embed themselves within the hospice. The identity badges and t-shirts that demonstrated membership of the hospice were worn with pride and they described themselves as hospice volunteers.

"I went to a birthday party and one of the parents ... asked me 'What do you do?'... I said I do a bit of volunteer work with Compassionate Neighbours. They said, 'What is Compassionate Neighbours?' I showed them my badge, I said this is Compassionate Neighbours and it's available at the hospice"
(IN11: Mike, Compassionate Neighbour)

Compassionate Neighbours described a source of pride in being associated with the hospice and interestingly described themselves very much as volunteers of the hospice. What became evident was that the project managers managed a fine line between allowing and indeed engendering this sense of connection on the part of Compassionate Neighbours with the hospice whilst also keeping them separate on issues where compromise would have been to the detriment of the project. They adopted something of a buffering role, required not only at the start but also throughout the life of the project. In addition to this, they served to create a new

space within the hospice – a space in which Compassionate Neighbours could exist as both members of the public and members of the hospice, drawing on support from each but transcending both worlds.

Whilst observing tensions arising between the project and the hospice, further tensions became evident along another boundary, between the Compassionate Neighbours project and the community development charity supporting it. The community development charity fought against the applications of hospice regulations within the project. They found the approach too restrictive and governed by rules rather than individual needs. An example of this was when a DBS check (which was required of all Compassionate Neighbours) revealed sensitive information, meaning one trainee Compassionate Neighbour would be unable to proceed to be matched and they were removed mid-way through a training session. A staff member from the community development charity describes the event below.

“The way [X] was treated was very bad. Somebody storming into the session, taking him off... I understand the reasons well but ... that behaviour is not acceptable, don't treat people like that. He has been as honest as he can, he is a wonderful, caring human being who has been so helpful... So he's not to be treated like... he's just a problem, because he's a lot more than that.”
(IN5: Jane, staff member at community development charity)

The staff member from the community development charity here conceded that hospice has governance procedures that were more restrictive than those of the community development charity and even though she did not agree with them, could understand why they are in place. What she disagreed with was the lack of focus on the Compassionate Neighbour as an individual who would have other skills to contribute and rather than evaluating these, he was simply removed from the course mid-way through a session.

The community development approach focused on people as the end point, the change in their resilience, capacity and confidence being key, which is why the way of dealing with the situation in the example above was experienced as so offensive; it ran contrary to these principles. The healthcare approach saw people, the Compassionate Neighbours in this case, as a means to getting to a further goal to care for the Community Member and so, in some sense, they were considered dispensable. The meeting of these two approaches in this project brought these

fundamental differences to light and the boundary between the two was a complex and contested space in the early, developing phase of the project.

6.4 Action Four: Participants act with autonomy

A strong theme emerging from the data was the opportunity afforded to Compassionate Neighbours to act with autonomy. Crucial to this autonomy was the giving of authority by the hospice, and the taking of control by the Compassionate Neighbours, lending a much-sought legitimacy to informal community caring. This was described by both by the project managers and the Compassionate Neighbours as a vital aspect of the project and the training was key to its successful enactment.

The first subtheme describes the autonomy participants had over their personal boundaries and conduct within the project. At the start of the training, participants would collectively outline non-negotiable boundaries for the project and they would be written on a flip chart. These then served as the collectively agreed rules of engagement for the training and project (Dc3: Boundaries of project).

Through the training participants would further reflect on how they felt about the negotiable or flexible aspects of the project, for example how they would conduct themselves when matched, where they would visit people, what they would do during the visit, whether they would share their mobile phone number or personal details about themselves and when to seek help or advice. The processes used in the training allowed people to see the diversity of opinion and behaviours within the group, and to understand that this was as it should be. People were offering themselves, not a set intervention and as such, each person would offer something personal and different. By way of example, in one training session, participants, all standing in the centre of the room, were asked whether they would share their mobile number with their Community Member. Those choosing 'yes' and 'no' stood on opposite sides of the room and those unsure in the middle. The spread of people in the room was wide and this was used to illustrate that there are no right or wrong answers to questions such as these, different people have different personal views and the important skill is to understand your comfort with an issue, where your position is on it and why. The project managers said that if they set strict rules about issues that were open to discussion, people would work around them, but covertly, and they wanted to avoid this. They emphasised during training and beyond that

Compassionate Neighbours should always discuss honestly what was happening in their relationships (PO18: Training day).

The second subtheme describes how Compassionate Neighbours enjoyed autonomy over how they conducted their role within the project. The lack of a requirement to complete a formal report on each visit and how they were trusted to develop the relationship as they felt appropriate further supported this expression of autonomy. Compassionate Neighbours often described this important aspect of the project.

“Yes, the lack of guilt, the lack of duty, lack of prescription, it’s a real... it almost transcends volunteering, which is where we want it to go. Yes, it’s those things that gives it its energy and joy”
(IN10: Theresa, Compassionate Neighbour)

Compassionate Neighbours could be observed to operate with differing levels of autonomy in the community:

Hannah wanted me to take her to Marks and Sparks ... as she was going to one of her sons’ for Christmas ... And I’d checked it all out with Vicky and I knew it was quite alright. I mean it was a risk but she’d thought about it, and I’d thought about it and we’d kind of said, over some time, we’ll go for it. And I’m not too worried and if the worst had happened and she’d fallen over or we’d had a car accident or something [pauses] I think we could have worked that out.”
(IN17: Laura, Compassionate Neighbour)

This autonomy was not necessarily something the Compassionate Neighbours brought with them to the project. The third subtheme describes how the interest and commitment to the project and its work was tempered by a fear surrounding caring for people in the community. Compassionate Neighbours specifically expressed fear on a personal level, about how to initiate such work safely, how to communicate with people and how to build relationships.

‘One lady lives in a cul-de-sac and ... she’s got several elderly people around her... she is a middle-aged African woman and the other people are white older people and ... she only goes up to them when their door is open because she doesn’t want to frighten them. She doesn’t want to invade their privacy but is really concerned to make sure they are well. So when their door is open ... she ... says, ‘Are you alright, can I do anything for you?’ and she then picks up jobs for herself from them. But she’s worked out this way of managing it.”
(IN5: Jane, staff member at community development charity)

This expression of fear continued when Compassionate Neighbours were matched to Community Members at home; some expressed anxiety regarding their one vulnerability in the community in the event that something were to go wrong. Compassionate Neighbours described the steps they were taking to protect themselves, such as bringing change and receipts back after purchasing items for those they were visiting and being reassured that closed circuit television was in operation in shared halls where valuable items were displayed. Within the description of these fears, many Compassionate Neighbours articulated a clear role for the hospice. They described this as the wish for a 'safety net' and to know that help and support was available should they need it. The knowledge that they were able to access support if needed helped allay these fears and built confidence in the Compassionate Neighbours.

CN Having you [the Hospice] as the backup, going just visiting ... on your own is quite different, but the security and the back up ... we have got you we can refer to.

CN There is a feeling of being safe, with someone to talk to if we need to come back and talk to someone.

(Compassionate Neighbours, Focus Group 2)

This fear was acknowledged by those working in the community development charity as a part of working with communities:

"It's amazing how people want to be part of something that will make it somehow legitimate... what they are doing anyway... The fact is that people feel that they need some form of permission to care for each other... I think it is about the ... professionalization of society, that we end up with only doing what we are told to do by professionals who know better."

(IN5: Jane, staff member at community development charity)

Within this quote, some ambivalence can be detected on the part of Jane. In some ways, the hospice giving authority or 'permission' to care for others can be seen to be potentiating the dependence on professionals, but also captures a facilitative role, where the hospice is able to support and develop autonomous community caring. This ambivalence towards the role of the hospice could be traced throughout the project. On the one hand there was an acceptance that the hospice had a role in developing this work. On the other hand, placing the role of the hospice as central to this work allows professionals to remain in control of such initiatives, regardless of intentions, and to unwittingly reinforce a continued dependence on them. The need of the community to gain 'permission to care' from the hospice encapsulates this

ambiguous role of the hospice and the complexity entailed in the concept of Compassionate Neighbours acting autonomously.

A final perspective on fear felt by participants relates to the fear of withdrawal of professional or state provided services. In one of the first selection days, people asked whether this was a means of getting cheaper or free care for the poor in society, whether professionals were just asking the poor to care for themselves? Whilst people accepted the need for care to be more personal and to involve communities and friends rather than just professionals, they expressed fear at being left with access to even fewer services than they had already. Some people reported how hard they had found caring for someone who was dying at home. They reported difficulty in getting professionals such as district nurses and general practitioners to come to the house (PO3: Selection day).

6.5 Action Five: A desire exists for control alongside company

The most common reason for being referred into the Compassionate Neighbours project was social isolation or loneliness (Graph 5, Appendix 1). This was not surprising as the promotional material described support for loneliness as one of the main offerings of the project (Dc1: promotional postcards for the project). A family member, the hospice or professionals in external organisations usually referred Community Members into the project. However, whilst interviewing Community Members, it was interesting to note that no one recognised themselves as lonely, and many refuted the idea that this was their experience. The first subtheme captures how Community Members contested the traditional or dominant narratives and assumptions about loneliness.

"I don't get lonely really, because as I say, I get out and about ... So I'm quite happy, you know. There's people worse off than me. So I don't grumble."
(IN16: Eileen, Community Member)

"I'm not really lonely, I'm just, low. Depressed. Nothing to look forward."
(IN12: Hannah, Community Member)

Instead of narratives related to the experience of social isolation prior to coming into the project, they instead described a series of relationships and experiences in which they had no control, as two community members confirm below:

"You say to someone, there's a list, you know, I want apples and I want that, they'll probably bring me the wrong kind, not the ones I want. So as I've always been so independent, it's very hard to leave it and give the responsibility to someone else... I used to read a lot, I can't see properly, I have to have big print and the library sends me books but they're not always my choice. When I used to go myself I used to pick what I wanted."

(IN12: Hannah, Community Member)

"In the past, they'd send people round... and they'd say they were coming and then they don't turn up."

(IN15: Brian, Community Member)

Whilst the accounts of both Community Members confirm a vulnerability inherent in living alone and being dependent on services to translate their needs and preferences, their stories also confirm a desire in each of them to exert control and to continue to be active wherever possible. This was translated in the detail of the relationships they developed with their Compassionate Neighbours. For example, Hannah was very specific about the kind of person with whom she would be willing to have a friendship, making her requirements clear and refusing to accept just anyone:

"I'm not ... elitist but someone of a similar ilk, you know."

(IN12: Hannah, Community Member)

She also controlled the rate of the development of the relationship with the CN who visited her.

"She [Hannah] will say, when I ring her up, to fix an appointment... 'We won't do it too soon because I won't have anything to say.'"

(IN17: Laura, Compassionate Neighbour)

This wish to assert control was recognised by Compassionate Neighbours. In this excerpt, a Compassionate Neighbour reports her first impressions of the Community Member, Joycelyn she was matched with:

"She was bedridden and struggled to speak but I had the impression she was strident and assertive, which I liked that because it meant she'd probably let me know if she didn't want me to visit."

(Dc10: Reflection by Compassionate Neighbour for internal collection of case studies)

Another Community Member, Brian, demonstrated his interest to exert control in the shape of his emerging relationship by becoming an active participant in its development. He and his Compassionate Neighbour, Mike, found a shared humour, which he noted with pleasure:

"He [Brian] always asks me, 'Would you like some tea?' and I say 'No, I don't drink tea' and he says 'Oh, but I would like to have one, could you go and make one for me.' Yes, and then when I make the tea, he tastes it and says 'Ah, that is disgusting! Ah, horrible tea!'"

(IN18: Mike, Compassionate Neighbour)

Together they negotiated new levels of trust and intimacy as they built a relationship that became long-standing and substantive in nature. This particular Community Member, Brian, actively engaged in the relationship, influencing and changing its course nature from formal to informal type, moulded to suit his needs and preferences. Brian could be seen to be moving himself into a position of being able to offer support and advice, alongside the Compassionate Neighbour, Mike.

The narratives of control and active participation rather than loneliness and passivity in the experiences of the Community Members were interesting. They appeared to create opportunities for reciprocity and these were welcomed and facilitated by the Compassionate Neighbours.

The rejection of the suggestion that they were lonely by the Community Members interviewed were in marked contrast to the stories of social isolation and loneliness offered by Compassionate Neighbours.

"I am learning that I'm not the only one in the boat, but I felt lonely [prior to joining the project]"

(IN7: Susan, Compassionate Neighbour)

Compassionate Neighbours also expressed concerns about how they felt they might become lonely in the future:

"I think stepping into retirement, I found it a bit scary, going from being part of a work community to being home based, although I'd worked a lot at home. I was thinking a lot about how make sure that I didn't become isolated."

(IN17: Laura, Compassionate Neighbour)

It is interesting to note how Compassionate Neighbours were able to refer to themselves as lonely, and they often described how this was a motivating factor for participation in the project, whilst the Community Members, who had been referred by others into the project precisely because they were perceived as being lonely, did not recognise this as a problem facing them. The potential stigma and its disempowering nature was identified as a possible reason for this by one of the external staff members:

“But ... someone coming into your house and telling you ‘I think you are lonely’ and you are ‘Oh no, I don’t think I am’. It could potentially be quite damaging and they might be wondering ‘Why is someone trying to put this on to me?’”
(IN14: Justin, external staff member)

6.6 Action Six: Formal regulations are enacted alongside fluid processes

The formal pathways set by the hospice and the more organic processes necessary in the community development nature of the project were often seen to be in opposition, leading to conflict. The first subtheme acknowledges this conflict, described more fully in *Action Three: Boundaries are fixed yet permeable*, whilst the second subtheme further describes how at times they could also work together, synergistically; to both meet the institutional requirements, whilst achieving the broader aims of the project.

The meeting of a community development project and a healthcare institution meant two opposing ideologies and sets of supporting principles were laid out next to each other. This led to predictable tensions and conflicts, often between hospice staff and the project managers or members of the community development charity. The differing drivers of the project and the hospice lay at the heart of these tensions. The project managers and community development charity staff saw the project as a means to maximise the participation of the community, in order to be as inclusive as possible; the hospice was more focused more on preserving the safety of the Community Members and Compassionate Neighbours, meeting funders requirements for numbers matched, ensuring the reputation of the hospice and conforming to regulatory requirements for the sector. This tension is well described by one of the senior managers at the Hospice:

“Whilst Compassionate Neighbours is at [the hospice], there are aspects about risks and keeping people safe – DBS checks and paperwork. We are dealing with society’s most vulnerable people... and that has made me nervous...”
(IN4: Debbie, Hospice staff member)

Counter to this, a project manager highlighted her key concern for the project and its overall goals of inclusivity:

“... everybody should have the opportunity to be a Compassionate Neighbour. Who are we to say they are not? “
(IN21: Vicky, project manager)

In order to ensure the progress of the project the project managers were often engaged in protecting the Compassionate Neighbours from these conflicts.

“one of the complex things about delivering this role [project manager] is not just about delivering the project, its... to stay true to what the project is... I have to constantly think about the big picture and about staying true to what the aims are of Compassionate Neighbours and about compassionate communities while battling ... with being sucked into the minute role of achieving targets or of doing what I am ‘supposed’ to do in the eyes of other people in the hospice”
(IN8: Vicky, project manager)

An example of how this tension manifested occurred when a staff member made a referral to Compassionate Neighbours for an elderly deaf lady. The team tried to find a Compassionate Neighbour who could sign but they were unsuccessful. On feeding back to the staff member that they would be unable to provide a Compassionate Neighbour, the staff member was shocked:

“She [staff member] said: ‘Well, I don’t think that really matters, ... you just need someone to go around and sit with him so his daughter can have a couple hours off’ ‘No, I am not doing it’. [Project manager] You know, it’s a constant battle ... they want respite for the daughter and I am not doing it. I am not having a Compassionate Neighbour whose entire training is about creating and building relationships, I am not having them going around and sitting with someone who can’t communicate with them, ‘cause that’s not what we’re doing here.”
(IN8: Vicky, project manager)

Whilst conflict existed between the project and the hospice, there were examples also of when they had adapted to work together, to allow each approach to realise its main goals or purpose, but whilst staying true to the requirements of each. A

good example existed in the negotiation and shape of the training developed for Compassionate Neighbours. The training course was aimed to be as inclusive as possible - few people were turned away at the selection days and efforts were made to accommodate all who expressed an interest and commitment. Similarly, the majority of participants who completed the course were selected to become Compassionate Neighbours. This meant the training and selection for this first step was highly inclusive, allowing people in to the project who would otherwise never have signed up to become volunteers in a hospice. What followed subsequently was a series of highly selective processes, run by the project managers, based on their in-depth knowledge of the participants developed during the interactive training. This included decisions about whether someone was suited to being matched to a Community Member currently, if so when this should happen and who should be invited to undertake different type of role within the project. The project manager describes this well:

"I really get to know them [participants] and I feel like I have a relationship with every single person who has been through the training. I know every single name, their personalities and characteristics. I really, really know them well, so I can match them well and I know their needs well."

(IN21: Vicky, project manager)

What is clear is that the inclusive and open processes at the outset enable the training to act as a standalone, inclusive community intervention around death and dying; in contrast, the more restrictive processes that occur later in someone's recruitment allow the project to operate as an intervention run by a hospice for those dying at home, compliant with the relevant policies. In this way the opportunities and challenges of a community development initiative in an established health care context are addressed.

6.7 Summary of chapter

This chapter has examined the actions observed to be taking place as the Compassionate Neighbours project was initiated and how a project following the principles of community development interacted with a healthcare organisation and traditional models of volunteering. It describes a complex relationship that moves beyond conflict or tolerance to one of synergy. Despite differences between community and healthcare institution-led approaches they both have something to

contribute and something to learn. Processes of compromise and negotiation run through these themes, as does a sense of creating something new, something that neither can do alone, is greater than the individual components and draws on a synthesis of the two approaches.

Chapter 7: Relationships as both process and outcome

This chapter is the second of the three chapters describing the findings of the study. It explores the experiences and perspectives of individuals who participated in or were affected by the Compassionate Neighbours project and describes the impacts that resulted from their involvement. It comprises stories of personal transformation, alongside, and in contrast with, those of intrusion, highlighting the personal level on which this project is experienced. Relationships and reciprocity can be seen to form a central thread, and experiences and impacts are explored in relation to these themes.

7.1 How relationships are experienced

Three groups with distinct experiences emerge from the data: Compassionate Neighbours, Community Members and the hospice. These three groups occupy different positions in the project and this influences their capacity to build relationships and to engage and participate in them. Compassionate Neighbours had the most significant opportunity to build relationships across the project with multiple different actors and they were observed to hold relationships with other Compassionate Neighbours, Community Members and the hospice. The Community Members were only observed to have the opportunity only to develop a single relationship with the Compassionate Neighbour they were matched with and the hospice was observed to develop a relationship with Compassionate Neighbours only.

7.1.1 The Compassionate Neighbour-Community Member relationship

Existing as peers

Compassionate Neighbours and Community Members often enjoyed a relationship in which they saw themselves as equals. This approach was underpinned by an acknowledgement that Compassionate Neighbours and Community Members were peers, living in the same neighbourhood, often on the same street, and commonly having similar needs to each other. The training provided to Compassionate Neighbours supported this perspective, as a key component was to understand how to develop authentic relationships between peers (as discussed in Action Two,

Chapter Six). It was clear that Compassionate Neighbours and Community Members searched for this commonality and allowed it to define their early experiences of the relationship. There were many examples of pleasure on the part of both Compassionate Neighbours and Community Members when they discovered things in common, such as television shows, favourite food or a favourite colour.

"Sometimes when I go to his house I just bring something for him because he likes carrot cake... like me [laughs] so we can share... and it's not only that, the extra 'wow' for me – he doesn't drink, like me, he never drink alcohol [sic], same as me which is very good. He does not smoke... I don't smoke, its brilliant! [laughs] So, it's amazing, it's amazing we just get on so well."
(IN11: Mike, Compassionate Neighbour)

At first these similarities could seem somewhat inconsequential but the strength of the emotion attached to them and the frequency with which participants repeated them to me urged me to look deeper. I came to understand that they demonstrated the foundations of the relationship - a relationship of peers. The fact that such similarities could be identified between Compassionate Neighbours and Community Members despite differences in age, gender, ethnicity and illness status was all the more significant. It became obvious that these efforts to find interests in common were attempts by both Compassionate Neighbours and Community Members to move their relationship from something formal, established by an organisation, to something more personal and informal in nature. This view was confirmed as I observed a practice development meeting with Compassionate Neighbours (PO17). The project manager was describing how awkward she often felt after matching a Compassionate Neighbour with a Community Member. They would often begin talking animatedly and she felt profoundly awkward, as though she was inhibiting what was happening and felt she should leave. A Compassionate Neighbour explained the reason for this, as it was a 'natural thing' to meet and talk with someone, but the presence of the project manager served to make it feel 'like a medical thing'. This again highlights the ambiguous role of the hospice, facilitating the meeting and relationship but at the same time undermining its authenticity.

Relationships of depth

Many of the Compassionate Neighbours and Community Members enjoyed sustained relationships, Graph 7 (Appendix 1) shows how 32/63 matches continued

either until the death of the Community Member or were still continuing at the close of the study. The relationships were also characterised by a depth of friendship and intimacy. This intimacy was best illustrated through gestures that demonstrated trust, for example giving someone your keys when they were running out to do an errand, through jokes made at each other's expense, or through describing the love that one felt for the other.

"Cos [sic] even when I went out yesterday, she says to me 'take my keys'... So for someone to entrust you with that and she's got her faculties, she's not stupid or anything like that, but to feel comfortable with that, that tells me the need and the impact that I have and she have on me [sic] to trust and that trust is not words to say 'I trust you', it's just there."

(IN1: Mary, Compassionate Neighbour)

In this quote, Mary is describing the relationship she had with the first Community Member, Belinda she was matched with. Her appreciation of the depth of trust established was made even more significant in the light of their differing ethnic backgrounds and her realisation that such closeness would have been unlikely outside the project. She goes on to describe the nature of their physical intimacy:

"It's a kind of loving-caring one [relationship] because one time she says to me, 'your hair, it interests me and impresses me' [as she asked if she could touch it] ... little things she shares with me, like she's got a sore bottom. Yesterday she said to me the doctors gave her cream, I say, 'Can you reach to...?' she said 'No, I'm going to sit on the toilet and apply the cream...!'"

(IN1: Mary, Compassionate Neighbour)

In this quote Mary use the term 'loving' to describe their relationship. In her second match with a different Community Member, Hilda she describes a similar experience:

"So when I'm leaving or it's late in the evening she [Hilda] says to me 'Be careful on the road, look after yourself' and 'I'll miss you, you know'. She'll say little things like that. And a few times she's said, 'I love you, you know.'"

(IN9: Mary, Compassionate Neighbour)

The development of reciprocity

Reciprocity was a defining feature of the relationship between Compassionate Neighbour and Community Member, and indeed of many of the relationships throughout the project as a whole. Each perceiving the other as a peer supported this expression, inviting both Compassionate Neighbour and Community Member to

bring themselves and their needs into the relationship. The wish of many Community Members to exert control, and be active participants within the relationship (as discussed in Chapter 6, Action Five) demanded space for reciprocity in the relationship. Its presence between Compassionate Neighbours and Community Members was enacted overtly and subtly. The sharing of food on both sides was a frequent manifestation of this aspect of the relationship, as was the offering of care and concern, through words and telephone calls. Mike describes how it developed in his relationship with Community Member Brian:

"[Brian] always asks, 'How is your family?' ... It's not just for me to visit him and care about him, he also cares about me. Sometimes he says to me, 'You are not working, have you got enough money?' He is really thinking about me."

(IN18: Mike, Compassionate Neighbour)

7.1.2 Compassionate Neighbour-Compassionate Neighbour relationship

Although the relationship between the Compassionate Neighbour and Community Member was the main focus of training and in fact the only focus for the funders of the project, it was clear that the relationships that developed between the Compassionate Neighbours themselves could be just as intimate, and that the training also supported their development. These relationships proved to be tolerant and accepting and lasted over many years. Compassionate Neighbours supported each other as they experienced their own life events such as illness, loneliness, caring and bereavement.

"When we came together, we did gel very well, without knowing each other and then [CN] suggested we create this whatsapp thing and then we just communicate with each other, you know, 'Have you got your DBS yet?' 'No I haven't' 'How's it going?' So that actually keeps us together. So just texting, keeping each other aware of what is going on."

(Compassionate Neighbour, Focus Group 2)

The depth of these relationships, their sustained nature, and their ability to support members through new challenges that emerged over the course of time indicate that the group of Compassionate Neighbours functioned as a compassionate community in its own right. For some Compassionate Neighbours who were not matched with Community Members, this network became the focus of their activity within the project, the new relationships they were developing adding meaning and purpose to

their lives. For some who had limited social networks outside the project, this community came to serve as their main source of support.

“Their sense of belonging, and place identity... they share with all the other Compassionate Neighbours, they did this training and they shared the experience, they’ve got shared concerns and worries, they’ve got the shared geographical environment and then they are going out to do this other thing [matching] which I feel is secondary. I honestly feel like the matching and the experience is secondary because they like it and they thrive when they go and see someone but what they love the most is coming back to PDM and telling everyone else about it.”
(IN21: Vicky, Project Manager)

The data from the service log seems to support this. Graph 6 (Appendix 1) shows how some Compassionate Neighbours engaged in multiple matches, but for other Compassionate Neighbours, they remained within the project but were not matched at all.

These individual level relationships were important but beyond this, there also seemed to be a further connection, to the wider group of Compassionate Neighbours many of whom they would never have met. This allowed a connection with a wider network of people, united with the same vision and purpose and suggests the development of a compassionate community of Compassionate Neighbours. When larger groups of Compassionate Neighbours came together, at events such as graduations or parties, many of the participants described being energised. They relished being part of something larger, brought together by the same values and practice:

“I found it really exciting at graduation... and I’d asked several friends and they were just bowled over. People who are still working, working in mental health, just bowled over... It was the diversity and the energy and the sort of joy... I think everybody is so sort of ‘wow’! You know, it creates that within the groups.”
(IN10: Theresa, Compassionate Neighbour)

However, not all Compassionate Neighbours participated in this compassionate community, or engaged in significant relationships with other Compassionate Neighbours. Some, as the project managers reflected, just wanted to be matched with someone in their community - the opportunity to connect with someone locally being their main aim. These were often people who were working, or new to the area, and whose interest was not a wider social network but an opportunity to embed themselves in their new neighbourhood instead. They contrasted strongly

with some of the other Neighbours, for whom the relationship with the Community Member was of secondary importance. The structure of the project facilitated these diverse experiences. Monthly practice development meetings, weekly drop in coffee mornings and frequent events on weekends and in the evenings provided the fabric of a social life, allowing Compassionate Neighbours who sought relationships to meet their own needs to find them quickly and easily, whilst allowing others to engage in events as they wished.

"I felt very socially isolated before, I didn't feel a part of my community, even though I've lived here in the same place since 1977... so yes, it has really revolutionised my world and there are people I can meet every week or every month and because we've got the Personal Development Meetings and we have coffee mornings on a regular basis and I get huge support from my line manager and from her manager so it feels altogether good; feeling bound in rather than ... you know just a little person somewhere on my own in the sea of strangers."

(IN6: Linda, Compassionate Neighbour)

In this quote, Linda provides us with a further insight. In describing her 'line manager' (the project manager). This sheds light on the perspectives of some Compassionate Neighbours who did not find the flexible and reflective methods used in the project easy to work with, finding the more formal structures of a volunteer-led service more comfortable.

7.1.3 Compassionate Neighbour-hospice relationship

The relationship between Compassionate Neighbours and the hospice as an institution was entirely different to the traditional volunteer-hospice relationships observed in the same organisation. Part of this could be explained by the efforts on the part of the project manager to situate Compassionate Neighbours as separate and different to other volunteers recruited by the hospice, as discussed in Chapter Six, Action Three, but there was evidence also of a different approach exercised by the hospice. Although this was often led by the community development charity or the project managers, the Compassionate Neighbours viewed it as coming from the hospice as an institution. The authority given by the hospice to the Compassionate Neighbours represents one of these differences, as discussed in Chapter Six, Action Four. Compassionate Neighbours, who enjoyed the autonomy with which they could operate, matched this authority given by the hospice with a taking of control:

"I really like that flexibility and although obviously we're not there to do practical things, if there was a nursing issues or a medical issue I would have had no issue in saying, why don't we ring up [the GP] whilst I'm here."
(IN17: Laura, Compassionate Neighbour)

The development of trust

A further example of the different nature of this relationship was the seemingly routine provision of lunch for the Compassionate Neighbours during training. The hospice usually provides a voucher to volunteers who have been working for more than 3 hours to obtain food, free of charge, up to a certain value from the canteen. The community development charity was clear from the outset that the training cohort would need to eat together during each training day. As a result, a table was reserved for them in the canteen, a practice normally reserved for patients or visitors of staff. In one training cohort, there was a group of 5 women from one ethnic group who were reluctant to eat the food from the hospice, because of the connotations with death and dying. In the second week of training, they came and took food away and ate it outside the hospice. In the third week of training, they brought the food they had chosen to the reserved table and ate and chatted with the other participants and facilitators (PO7: Coffee morning). This example illustrates two key points. The first was that the hospice was challenging its own perception on the role and position of the Compassionate Neighbours in the organisation, by publically sanctioning their importance with a reserved table in the canteen, a highly visible setting and one with engrained rules of behaviour and hierarchy. Secondly, the offering of this act of respect and value on the part of the hospice was acknowledged by the Compassionate Neighbours, and succeeded in altering opinions regarding the hospice in a way that simply participating in the training course had not managed to. The eating and sharing of food together was seen as an intimate act and it demonstrated the development of trust between the Compassionate Neighbours but also with the hospice. The community development charity were aware of the importance of this, as this was an approach they usually used with community work. Theresa describes this in her own words:

"In the beginning I used to say, I don't know why we're having this food, it must be taking far too much money... It's a waste of their resources, we shouldn't be having lunch every time we meet. But actually, people feel very valued and very cared for... It's not at all a waste, it's a big, big bonus. People feeling valued and cared for, because that's what you're rolling out, that's what you actually want to achieve."
(IN10: Theresa, Compassionate Neighbour)

The enactment of reciprocity

The development of trust and respect between the hospice and Compassionate Neighbours appeared to lay the foundations for reciprocity in this relationship. Compassionate Neighbours felt they were benefitting from the training and participating in the project and described how, as a result, they felt it their duty to challenge stigma relating to the hospice in the wider community, and to share their positive experiences. This was not asked explicitly of the Compassionate Neighbours. One Compassionate Neighbour remarked to me during a coffee morning that she saw herself as a 'foot soldier' of the hospice, combatting the prevalent attitudes (PO12: Coffee morning). Another describes the consequences of his sharing his experiences widely:

"There is a lot more people in the school who know about it [sic], not just one teacher but almost everyone. Everyone in the school knows about it [the Compassionate Neighbours project]."

(IN11: Mike, Compassionate Neighbour)

The reciprocity enacted within the relationship between Compassionate Neighbours and the hospice afforded both partners an equality that was not evident in other volunteer relationships within the hospice. The Compassionate Neighbours were not undertaking a role on behalf of the hospice, but rather being supported by it to care for others as they saw fit. The project appeared to have successfully negotiated a new means of interaction and even partnership between lay community members and the institution of the hospice. The project manager reflects on how Compassionate Neighbours express this reciprocity and feeling of ownership by the hospice:

'They feel like they've got the keys to the place'

(IN21: Vicky, project manager)

7.1.4 Community Member – hospice relationship

The rich descriptions of the nature and impact of the relationships between Compassionate Neighbours, Community Members and the hospice, serve to highlight, in stark contrast, a paucity of descriptions of the relationship between the hospice and Community Members. Some Community Members were already patients of the hospice and were referred into the service by hospice staff, whilst

family members, their general practitioners, sheltered housing managers or social services, served as referrers of others. Community Members made only limited mention of the hospice, and this was often around the overcoming of their fears surrounding the institution. That this relationship appears underdeveloped is an interesting assertion in itself. The project structure did not offer the same opportunities for connection with the hospice, nor the wider network of Compassionate Neighbours for Community Members. This inequity was recognised by project managers who described plans they had to rectify this in the future. One ambition on the part of the project managers was to open the weekly coffee mornings to Community Members and invite them personally to the large social events that took place a few times a year. A number of Community Members attended a Christmas party with their Compassionate Neighbour. Some Community Members had attended these events previously and project managers reflected that they had gained a great deal by understanding and participating in the wider membership of the project (PO16: Coffee morning).

7.2 Impacts of the project

7.2.1 Impacts for Compassionate Neighbours

Connection

The strongest theme to emerge from the data regarding the benefits of these relationships focused on feelings of connection, as described by one Compassionate Neighbour:

“This is the first set of people I think I have connected with because I have only been speaking to people on the phone and working on computers... I don’t know any bodies, physical bodies... People to talk to and I don’t have to pay them.”
(IN7: Susan, Compassionate Neighbour)

This Compassionate Neighbour went on to explain how the connection with the group of Compassionate Neighbours had given her the impetus to reconnect with the wider world – beyond the compassionate community, getting a passport, driving licence and mobile phone.

“So after I graduated [from Compassionate Neighbours] I got my passport and my driver’s license... I am back on the radar.”
(IN7: Susan, Compassionate Neighbour)

The feelings of connection translated into a sense of wellbeing for many. One of the Neighbours, who had been involved in the project for a year, described this positive shift:

“Oh God, smiley, happy, just, I feel good within myself. It’s a feel good factor.”
(IN1: Mary, Compassionate Neighbour)

The strong sense of connection that many Compassionate Neighbours described was enhanced by an experience of intimacy and acceptance within the group, developed during training, even when they felt at risk of being perceived differently. One Compassionate Neighbour discussed her concerns about disclosing her sexuality to others and her surprise when others expressed acceptance.

“I had said [I was worried] about how my sexuality would be accepted or not and she [Mary] said, ‘Did you have that feeling about me?’ And I had to say ‘Yes’. I mean I find her a very spiritual woman and possibly a religious woman but she was well up for that conversation”
(IN10: Theresa, Compassionate Neighbour)

Personal transformation

The narratives from the Compassionate Neighbours were full of stories of personal growth and transformation. Many described the profound effect the training had had on their lives, allowing them to make sense of previous experiences and have the strength to move forward.

“... so now I think I’ve got a way, I understand some questions that I couldn’t find answers to. I come into ... Compassionate Neighbours, [doing] some background reading of what life is basically, and the cycle that I am on and I think I am beginning to learn to cope”
(IN 7: Susan, Compassionate Neighbour)

For some, this was about making sense of a particularly difficult relationship within their close network, such as Linda and her daughter:

“So this is a good counter balance, becoming a Compassionate Neighbour, to realize that my own daughter with whom I have such a difficult relationship, with is part of those people out there, as I am one of those people out there.”
(IN6: Linda, Compassionate Neighbour)

The opportunity that Linda describes, in which she was able to see her personal challenges in a context or network broader than her immediate world, is further reflective of the peer relationships established with Community Members. They were effectively equals, on the same journey and experiencing similar difficulties.

Other participants described spiritual changes as significant:

"I have quite strong feelings about Christianity and Catholicism I couldn't manage it before, I just had to avoid it and denigrate it. But now [following Compassionate Neighbours] I can manage the fact that I used to be a Catholic but I'm not anymore and it's lost some power over me, it had terrible power."

(IN10: Theresa, Compassionate Neighbour)

For Theresa, spiritual issues also became the focus of the relationship with the elderly housebound man she visited. She had found it hard to move from polite conversation in the early stages and was questioning whether the visits were helping him in any way. One day, out of the blue, he asked her whether she believed in hell. They had a discussion about Catholicism and he confided that he had carried a conviction that he was going to hell all his life after a conversation he had had with a priest as a child. They were able to explore this together and both came to the conclusion that it did not in fact exist, leading to a deepening of their connection, a sense of peace for the Community Member and a sense of happiness and pride in Theresa, who felt in a small way she had changed this gentleman's life and that this was also intertwined with her own personal journey (PO8: Coffee morning).

For others the growth or transformations were less reflective and more practical in nature. This Compassionate Neighbour who had been a full time informal carer for many years describes the impetus this had given him to get up and get dressed in the morning, and how this had translated in to a pride and interest in his life more generally.

"I never dressed up, I never made myself feel good and change the clothes. [sic]... I looked scruffy every morning because I was not looking forward to doing things. I wore things like pyjamas and jumper and t-shirt... but now, I am always looking forward to something. When I wake up in the mornings I say 'Yes!' You know, Wednesday is the course, I'll dress up a bit, put on clothes and go out and meet other people and talk to other people. "

(IN11: Mike, Compassionate Neighbour)

For Mike, the way he dressed was a representation of his self-esteem and his sense of meaning and purpose. The change that followed during the training course was a significant change. One of the participants in his training course, who was blind, expressed surprise when she heard his voice for the first time in week three and asked 'Who is that person?' Mike had been silent until then but had gradually developed the confidence to speak and participate. This change was recognised by his family and community, who in turn supported his continued involvement (PO19: Practice development meeting).

Interestingly the Community Member that Mike visited, called Brian, also took the participation in Compassionate Neighbours as an opportunity to dress up. Mike notes how smart he looks for each of their meetings and describes the moment he realised what an effort Brian made before their meetings.

"At one time I got to his house – normally I turn up at about half past one but that time I had nothing to do so I turned up about 1 o'clock and he was still in his pyjamas! He said 'Oh, I thought you were the postman I am still in my pyjamas, I need to go changed and everything. You didn't tell me you were coming early'"
(IN11: Mike, Compassionate Neighbour)

For some the personal growth had a more external focus, a sense of having purpose in the community or being recognised.

"I didn't not feel valued as a pensioner... I value myself... but I really do like having a purpose. I've got a purpose, you know, in other worlds, but in my own community, I really, really like having a purpose."
(IN10: Theresa, Compassionate Neighbour)

Further formal volunteering opportunities often followed Compassionate Neighbours training; with participants feeling the sense of confidence they had developed allowed them to pursue new opportunities.

"So I was really passionate about this course. I came in, I really liked the training, the role-play and listening to other people, it was good. And after that I joined more voluntary stuff..."
(IN20: Fathima, Compassionate Neighbour)

The observational data supports this, with Graph 8 (Appendix 1) demonstrating the further opportunities that opened up for some Compassionate Neighbours, with some entering employment as a result.

Changing attitudes

Attitude changes were described frequently, with most Compassionate Neighbours citing a change in their attitude to the hospice as being one of the significant impacts of their participation in the project.

“... because for me, the hospice meant something totally different, a dead end place. In my mind it was death, and death and death. And most people I meet now, they have the same idea that’s still embedded, so it’s for me now to give people different set up about the hospice because of being part of ... being part of it so I’m able to enable people to see or take on a different view.”

(IN1: Mary, Compassionate Neighbour)

This quote from Mary describes her sense of duty to dispel others preconceptions about the hospice, partly because of her new insights but also, as she pauses to reflect, because she now feels a ‘part of it’. This relationship between the Compassionate Neighbours and the hospice, characterised by a feeling of belonging and connection, appeared to motivate this Compassionate Neighbours and others in their actions. A story read out at a graduation builds on this idea of the hospice being a visible working part of the broader community, rather than hidden behind closed doors:

‘I was amazed at how much is going on at the hospice – it’s like a market place, so busy. I thought, ‘I’d like to be part of this, I’d like to be part of the work of [XX] hospice’

(PO9: Graduation)

Compassionate Neighbours often appeared to develop an appreciation of the experience of suffering, particularly related to living with frailty or a life limiting condition. For some, this was direct, through sharing the lived experience of a Community Member but it could also be through the awareness of the suffering of other Compassionate Neighbours or the more abstract reflection on what makes life worth living. This awareness prompted Compassionate Neighbours to reflect on their own lives and what was important to them. Some considered where they would like to die; others began having conversations with family members about their

wishes, others reflected on how they could avoid social isolation for themselves in the future.

“So ... thinking about end of life and how we all need to prepare individually has been a good step of learning about those things, doing the training, getting to grips, can you get to grips with dying and death? I don't know but I mean, I am getting closer to it and that has been totally beneficial for me as a person.”
(IN6: Linda, Compassionate Neighbour)

“For me, it's helped me with other friends and family where death is an issue. Because you have to look at it and realise, it will happen to us all. It helps to be able to talk about it more. That is very helpful, if people in the community can talk about it more then it takes away a bit of the sting, I think.”
(IN17: Laura, Compassionate Neighbour)

Compassionate Neighbours regularly described shifts in their understanding and expectations of community life: what being part of a community means, who composes communities and how tolerance or compassion can be expressed more widely in communities.

“I think because in life we're all in this chain... we're all different stages in the chain of life and ... we all belong, we all belong... Community for me now is something different, something else, not just the community of the church, or the people that I know or used to, or friends or, those are there and they have their place but wider than myself and my immediate family, the world is bigger and wider than my space, so you can embrace people.”
(IN9: Mary, Compassionate Neighbour)

7.2.3 Impacts for Community Members

The experiences of Community Members contrast with those of Compassionate Neighbours. Specifically, there were few narratives of personal transformation, new or increased confidence and only limited discussion of connection and belonging. The most striking and positive benefits for Community Members were those arising from a sense of participation in the relationship with the Compassionate Neighbour, and the agency generated through active engagement with someone else. By contrast, some experienced the involvement of Compassionate Neighbours in their life as an unwelcome intrusion and challenge, given all else that they were facing and managing.

Active participation

As described in Chapter Six, Action Four, it was often not company that Community Members sought, but a sense of control. Here, the impact of participating actively in a relationship is considered.

For Community Member Eileen, the active participation in relationships was expressed through food. She described a longstanding relationship she has with her next-door neighbour that emerged when she was unwell. They took it in turn to host each other for dinner each day, one cooking the other a meal alternately.

"[with] the lady next door, one day I do the dinner and the next day, she'll do the dinner. So if I do it today, she'll do it tomorrow... And she always does it on Sunday, I do the breakfast and I take it into her in the morning and then she makes the dinner."

(IN16: Eileen, Community Member)

Eileen explained this in the context of how she relates to the Compassionate Neighbour who visited her:

"And [Compassionate Neighbour] comes straight from work, so I make her sandwiches and tea... Have biscuits and cakes and things like that... And she says, 'I should be doing it for you!' I say, 'Well I'm here all day, you're coming from work.' As I say, I'm very lucky in that way."

(IN16: Eileen, Community Member)

Eileen appeared to be replicating the role and relationship she enjoyed with her neighbour in her relationship with her Compassionate Neighbour, within which she positioned herself as a carer, regardless of any protestations on the part of the person she was caring for. She gives us insight about the value of adopting this position, confirming that this is how she maintains a sense of self as an elderly woman living alone.

She goes on to reflect:

"I used to do a lot of knitting... but with the arthritis I can't do it anymore... I miss that so much. I read books and I watch the telly, so if there is nothing good on the telly, I just turn it off and read a book. So I read quite a lot of books. So I'm quite happy, you know. There's people worse off than me."

(IN16: Eileen, Community Member)

Whilst Eileen acknowledged the losses she had faced, she held high the ability to continue to be an active person. This was enacted in her relationships, in which she assumed an active role, allowing her to maintain the sense of being 'lucky', a word she used frequently, to confirm that there are people in a worse situation than her.

Having a relationship with a Compassionate Neighbour enabled many Community Members to re-engage in activities that had become impossible for them due to their reduced physical capabilities. For some, the opportunity to reconnect with old friends, outside the house, was particularly valuable as it enabled them to retain a sense of who they were as people. One Community Member and his wife laughed about the response of their Compassionate Neighbour when he took the Community Member out in his wheelchair:

Researcher: So when Mark [Compassionate Neighbour] takes you out, you said it's like a social meeting?
Sue: Yes, more or less, yes. Tom says he's never known anybody with so many... [laughs and gestures]
Researcher: Friends?
Sam: Yes, I know so many people
(IN:19 Sam and Sue Community Members)

Some Community Members were specific with their requests from the project from the outset. Graph 5 (Appendix 1) shows that a sizeable minority of Community Members were referred into the project for help undertaking a specific activity rather than for social isolation. This included a request for a Compassionate Neighbour who was available on certain days, to take them to bingo or attend church. In so doing, the nature and reciprocity of the relationship appeared secondary to the primary aim of continuing to be able to live their lives, the Compassionate Neighbour providing a means of retaining this.

An intrusion and unwelcome challenge

For a minority of Community Members, the relationship with a Compassionate Neighbour served more as an intrusion than a welcome opportunity to create a new relationship. The service log data (Graph 7, Appendix 1) demonstrates that 8/63 matches were terminated by the Community Member, suggesting both that some felt this project was not meeting their needs and they felt able to exit from it. Some Community Members who chose to terminate the relationship described a daily routine which helped them cope with the demands of their life; consequently a visit

from a Compassionate Neighbour represented an unwelcome intrusion into that routine, and requiring further effort or energy to accommodate, as the Community Members below described:

"It [a previous person visiting] was through one of these things that send befriending services. And they are very nice and all that but I mean. If they come, I feel I've got to make them a cup of tea and all that, I haven't got the energy... I can't be bothered."

(IN12: Hannah, Community Member)

As this Community Member described, the sense of intrusion lay in finding a balance between the benefits the relationship potentially confers and the effort required engaging in it. The effort required was not experienced as the same between individuals. For Hannah, it was a negative experience, using up energy that is perceived as a finite reserve. For others, however, expending effort in receiving or hosting a visitor such as a Compassionate Neighbour was seen as a positive experience, allowing an active participation in a relationship and the opportunity to express care, affection or support.

Theresa, a Compassionate Neighbour, speaks here about her difficulties as she realised that the first Community Member she visited was not finding her visits helpful and did not really understand why she was visiting her:

"She wouldn't say 'I don't want you to come' but she was saying 'I don't really know why you do it?' When I'd gone first she used to say that but that felt more about why do you do this for yourself. I didn't feel it was like 'why are you doing this to me? But then it began to feel a bit like that, why are you doing this?"

I think she genuinely didn't want... any interruption really... she'd decided how she was going to manage, she wanted to sit in that chair and she would somehow manage herself in it... And I think that was her philosophy of life. And I think I interrupted that."

(IN10: Theresa, Compassionate Neighbour)

The control that Theresa confirms is important for her Community Member is linked to her desire for independence. For many, a mutually supportive relationship with someone else served as a positive coping strategy and something that helped them cope with their lives. For others, however, independence felt most important and anything that compromised that ability was experienced negatively. Hannah, a Community Member remarks:

"I want to be left alone to a certain extent, but to be self-supporting."
(IN12: Hannah, Community Member)

There was an expectation from training and throughout the course that not all matched relationships would work. This was taken to be a natural outcome of people being matched, as one of the project managers explains:

"We've put people together and they have literally fallen in love and other people that immediately it hasn't worked and there's been people over a series of time that it hasn't worked."
(Focus Group 1, project manager)

This reflects the subtle distinction between a project that matches people in the community in order to achieve a goal for one or other party, as compared to a project that aims to develop authentic relationships between people as the primary outcome. This is supported by the graph capturing the outcome of matches (Graph 7, Appendix 1). The Compassionate Neighbours project accepted the variability of authentic relationships and therefore expected a certain number of relationships to fail, as a certain number would flourish, and that it was difficult to predict such outcomes from the start.

7.2.4 Impacts for the hospice

Staff members and volunteers

Members of staff working at the hospice or traditional volunteers recruited outside the Compassionate Neighbours programme represented an important group of individuals affected by the Compassionate Neighbours project. For many, the influence was indirect; they were not working on the project themselves but had some interaction with it. Their views regarding the project and its benefit were variable. Many members of staff, particularly those more senior in role, welcomed this project as a means of addressing some of the broader challenges facing the hospice.

'Initially we had a sort of patriarchal approach... tell us what you need and we'll deliver it... We are now at the stage that a lot of issues... are not medical, they are not clinical, they are complex. So much is about housing or money or relationships or isolation and with the best will in the world... there is no way in our present configuration that we will be able to deliver it all.'
(IN2: David, senior management team, hospice)

The principles of compassionate communities had been discussed in the hospice for a number of years prior to the Compassionate Neighbours project being started. These principles were felt to be in line with a strategic objective of the hospice, which was to improve access from groups not currently accessing the hospice.

'That we continue to develop local projects that help us serve the diverse communities that live in our area'
(Dc2: Hospice Strategic Direction 2012-2015)

A range of projects had been developed to support this aim, one of which was a redesign of the reception space to include a public space, with a café, seating area and gallery area, a piano and sheet music. Despite an explicit corporate strategic aim underpinning the Compassionate Neighbours project, there was evidence of resistance by members of the organisation in relation to this initiation. By way of example, some staff refused to refer potential beneficiaries into the new project; Compassionate Neighbours could be made to feel unwelcome in the restaurant area and at reception, and efforts might be made to reduce the size of the physical space and chairs available to them at their public meetings (PO7-9, PO11, PO16). I observed how these acts were often carried out covertly or anonymously. The following anonymous quote shows the anxiety projects designed to bring the wider community into the hospice created for some staff members:

Was the idea of the community hub not an ill-conceived idea? [X] Hospice is quite simply a place where people come to die in peace and relatives can collect their thoughts. I honestly believe that opening our doors up to the whole of [borough] and beyond in the shape of a community hub detracts from what we are designed to do. This in turn is actually putting our patients at high risk. The fact that we are happy to welcome potentially undesirable people into our grounds is a disaster waiting to happen. At the end of the day we are a hospice –not a social club!
(Dc8: Question and Answer session with Senior Management Team)

The project seems to represent a deviation from the core business of the hospice, believed to focus on providing care for the dying and their families.

Staff members supportive of the project could have unrealistic expectations about what Compassionate Neighbours could achieve. One social worker referred cases into the project, expecting this action to serve as a final point of handover – at which point she could 'close the case', confident that the project would in effect take over the social aspects of care of the patient.

“One of the social workers... rang me up and wanted to close all her cases, with me as the kind of outcome with her... People are looking for positive outcomes for their patients, well their service users, and they see this as one. But that’s wrong, because we are not doing anything for anybody. We’re not actually doing anything for anyone. And if loneliness was the only problem that they had, fine but even that, only once a week doesn’t solve loneliness.”
(IN8: Vicky, project manager)

Changes in local attitudes towards hospice

Section 7.2.1 describes the changes that took place in Compassionate Neighbours’ attitudes to the hospice as a result of participating in the project. Further to this, these changes in perception were observed to lead to behaviour change. In this example a Compassionate Neighbour describes how a person came into the hospice for end-of-life care as a result of her son hearing about the graduation from a friend.

“...my son ... brought [X] to my graduation who is best friends with the son of the woman ... which meant that when they were all so worried about her, [X] could say ‘Well it’s [the hospice] a lovely place, I was there with mum and there is lots of fun’. I think the more kind of tendrils that are out in the community about, what the hospice is really like, it changes, it can change people’s fears about death, it sort of defuses it and make it feel like this is something we can all be involved in rather than people have to go and hide away somewhere.”
(IN17: Laura, Compassionate Neighbour)

This demonstrates the impact that peer knowledge and affirmation can have on initiating behaviour change and shows the mechanism for how the Compassionate Neighbours project was able to influence community attitudes and then the patient profile of the hospice.

Compassionate neighbours saw this as part of their role as demonstrated in an incident observed during one of the coffee morning meetings:

During the coffee morning, a middle aged Somali man saw two Somali women walking out of the main part of the hospice and through the reception area, past the table where coffee morning was being held. He stood up immediately and went over to speak to them. I found out later that he did not know them but recognised them as Somali and wanted to find out what they were doing here, to tell them about compassionate neighbours and his role here and to welcome them into the hospice.
(PO14: Coffee morning)

Changing hospice practices

I observed how over the period of the project, the practice and principles of the Compassionate Neighbours project began to influence wider hospice practice and feature in the mainstream discussions of the hospice (Dc7: Article in hospice magazine). For example, the way in which the DBS check was carried out by the volunteering department for people who were not fluent in English began to be more accommodating and more support was offered by the volunteering team in gathering the relevant paperwork. The twice-yearly volunteer party, which had seen decreasing attendance, was merged with the party for Compassionate Neighbours that had high attendance, when a senior member of staff realised the disparity between the two. She spoke of realising the energy that was contained within Compassionate Neighbours and hoping it could energise other departments (PO16: Coffee morning). At times changes were called for by general volunteers in the hospice, interested in becoming more involved with Compassionate Neighbours. A number approached the volunteering team with a request to take part in the Compassionate Neighbours training. Discussion between the volunteer department and the Compassionate Neighbours project managers ensued and it was decided that all hospice volunteers would be offered the opportunity to participate in Compassionate Neighbours training. I learnt subsequently that this change was only partly implemented in practice. The volunteer department did not feel all volunteers had the capacity to train as Compassionate Neighbours that they would pick those they felt should participate (PO14: Coffee morning). This demonstrates how the conflicting goals of maximising participation versus maintaining the control of the organisation continued to express themselves despite changes with the organisation and the subtle enactment of power within such structures.

7.2.5 Impacts for the wider community

The project had a strong presence in the wider community. I observed at public events such as graduations (PO5 and PO9) how Compassionate Neighbours presented their work to the rest of the community. For the first graduation, a series of t-shirts were produced with the statement 'This is what a Compassionate Neighbour looks like'. This appeared to me quite a confrontational statement and quite questioning or challenging to others. This seemed to be set apart from the outward presence of other hospice projects that held a more passive external image. Compassionate Neighbours described to me later the questions they would receive

from members of the public when wearing it. One Compassionate Neighbour remarked that she liked the impact it had in public spaces; people would begin talking to her and she would use it as an opportunity to speak about the project and the hospice (PO13: Practice development meeting).

This questioning stance of the project continued in public events held out in the wider community. At one event held in a community garden (PO15: Community fair), I was surprised to see how Compassionate Neighbours approached members of the public. It was not a gentle approach, but a bold one, asking them if they were undertaking the role of being a good neighbour in their lives. They appeared to be working on a shared assumption that everyone wanted to be a good neighbour. This was captured in the banner that was displayed by their stand that asked 'Are you a compassionate neighbour?' (Dc9: Photo of banner).

Evidence of the impact of Compassionate Neighbours on the wider community emerged during the project. Some of this was quite direct, whereby individuals beyond the project and the hospice confirmed how the project had influenced their practice. Other evidence of impact was more indirect.

Compassionate Neighbours described how their participation in the project changed their attitudes to others in the community, making them more tolerant and accepting of others. For some, this went further and they described how their behaviours had changed significantly since their participation. Mary described how different she felt walking down the street:

"On Sunday I saw a lady and obviously she wasn't well... walking down the street, half dressed... and I have this smile on my face and I said 'Good morning' and she went 'Hello, good morning'... she was shocked... I look at people and I see things in different ways... my heart is at a different place."

(IN9: Mary, Compassionate Neighbour)

This impact was evident also in paid carers. The experience of one paid social carer who undertook the Compassionate Neighbour training demonstrates how her involvement in the project had changed her interest to care for someone beyond that demanded in her job:

"Last week one of the people I take care of, she called me... and she asked me if I could go to Sainsbury's early and buy [her] a gluten-free product to have tea with her friend... Usually I would say 'No, I am not paid to do that' And I said, 'Ok!'. I went to Sainsbury's, paid £2 for parking, got the things for her. I'm supposed to finish at 5pm, 5.30pm I'm still there and I think, 'Oh, how I'm changing. It's because of Compassionate Neighbours!' Because before I would not have done that. No, I would have thought 'It's my time.'"

(Compassionate Neighbour Focus Group 2)

This paid social carer's surprise at her own changing compassionate behaviour, which she attributes to the Compassionate Neighbours training demonstrates the impact participation in such a project can have on people unconnected with the work.

Compassionate Neighbours recognised the positive way their visiting was received by the wider community. This was particularly true for those also supporting the Community Members at home. Formal service providers such as paid social carers and general practitioners also witnessed the role Compassionate Neighbours were playing in the care of those in the community. The same Compassionate Neighbour, Mike describes his interaction with Brian's general practitioner (GP) when he meets him at his home:

"I went in and I met his GP. His GP was cycling and came and visited him at home... The GP just introduced himself and said 'Who are you?' and I said my name and that I am from [X] Hospice, Compassionate Neighbours and I come to see Brian once or twice a week. The doctor said he comes in at least once a week, once or twice a week too, when he's sick he comes twice a week."

(IN18: Mike, Compassionate Neighbour)

This interesting interaction between professional and lay caring networks confirms a potential working interface between the Compassionate Neighbours project and the wider professional community. Many Compassionate Neighbours mentioned that they had met their Community Member's GP and that the GPs were often surprised and pleased to meet a Compassionate Neighbour in person, particularly as some had referred people into the programme (PO7, coffee morning). In this way, we can understand how Compassionate Neighbours are providing a visual and tangible example of how communities can care for people and how community networks interface with professional ones.

Following from this, I observed how the action of Compassionate Neighbours supporting people in the community was not always welcomed or appreciated.

During a participant observation episode of a home visit with Compassionate Neighbour Mary (PO6), the daughter of the Community Member, Hilda, repeatedly expressed to me that she did not know why her mother needed anyone else to visit her, as she was always there and available. She appeared to feel that the presence of Mary somehow undermined the care she was offering as a daughter. Hilda had said to Mary many times that she needed the visits, as she could not talk about the things she wanted to with her daughter. She wanted to talk about her homeland and of a son who had died. Her daughter felt these conversations were repetitive and upsetting. This was again evident when a sheltered accommodation manager spoke to me about her view of the situation in which one of her residents, Hannah, was being visited by a Compassionate Neighbour, Laura. She felt aggrieved that Hannah needed support socially from outside and expressed frustration that she never attended any of the social events she hosted. Hannah had described the issues she had with the social opportunities in the sheltered accommodation during our interview.

"There's no one of similar... you know. Who you could have a discussion with... They'll [others in the building] gossip, about this one or that one but you can't have... I went down to empty some rubbish and there were two women sitting there... I said something, it was the time when the mayor [London mayoral elections] and all that. I said 'what do you think about it, who...' 'Who cares' they said, 'Who the hell cares. We don't even bother to vote.'"
(IN12: Hannah, Community Member)

Hannah does not feel she should have to accept any opportunities for social contact that are offered to her. She wanted opportunities that allow her to have the conversations that support her to continue being who she was. The sheltered accommodation manager appeared not to appreciate this, instead feeling that Hannah should come to all events provided. She appeared again to feel that Compassionate Neighbours was undermining the care she was providing or possibly highlighting its inadequacies. This is an important consequence of such work, that it unwittingly challenges existing support structures operating in the community and whilst for some they will act as a support for them, for others it may dismantle or undermine them.

7.9 Summary of chapter

This chapter has described the experiences of those participating or affected indirectly by the Compassionate Neighbours project. It highlights the key themes of reciprocity and equality that run through many of the relationships and describes, through the impacts, how this led to significant changes for individuals or the hospice. Whilst equity existed within many relationships, an inequity across the project was highlighted. Compassionate Neighbours are seen to have opportunities to benefit from a wider range of impacts as compared to the Community Members. This is due to their relative positions they occupy within the project.

Chapter Eight: Mutuality as a new basis for interaction

This chapter is the final of the three chapters describing the findings of the study. It follows from the two previous, largely descriptive chapters, to take a more analytical perspective. It asks what underlying drivers or processes take place within the project and lends a theoretical weight to their analysis. These processes act as the bridge between the observed actions taking place within the project in Chapter Six, to the impacts and experiences described in Chapter Seven. They illuminate the deeper, often unconscious processes that take place throughout the project. In keeping with grounded theory methodology, these themes understood in more abstract and theoretical terms are termed categories. Three categories emerged from the data:

- 1) Altered power dynamics between actors
- 2) Relationships defined by reciprocity
- 3) Building a sense of agency

These categories will be explored in detail in this chapter and serve as the building blocks for the next chapter, in which the theory emerging from this study is presented.

8.1 Altered power dynamics between actors

One of the fundamental processes taking place within the project was the acknowledgement of power that existed within all relationships and the resulting effort to rebalance these relationships. The prominence of the theme of power can be appreciated when looking at the six actions described in Chapter Six. These actions catalogue what is observable within the project, describing what is happening on a day-to-day basis. Themes such as autonomy, control, enforcement of boundaries and regulations all describe different aspects of the power relations inherent within this project.

Power and exclusion

The role of power in perpetuating social exclusion was highlighted to the hospice by the community development charity in the first project meeting and the on going attempts to understand, explore and mitigate these influences served as a constant source of discussion and often tension within the project. The community development charity set a number of non-negotiable requirements from the outset; these were deemed essential if this project were to take place on a different basis of

power to traditional hospice volunteering projects. Examples of such requirements are captured in Chapter Six through actions such as *'Boundaries are fixed yet permeable'* and *'Formal regulations are enacted through fluid processes'*. These describe how hospice procedures that would otherwise exclude participants on the basis of language or not having correct documentation were adapted. The practice of not allowing patients to become volunteers was changed and the structure of open days, selection days and the course itself designed in a way that facilitated the engagement of the community rather than designed on the terms of the hospice. This different frame through which Compassionate Neighbours was understood to act through within the hospice was clearly initiated by the community development charity and took a great deal of effort on the part of the project management team to ensure it was protected and not diluted as the project grew and assumed a more central role in the hospice. One of the most important impacts of these changed structures and consequently altered power dynamics was the diverse cohort that formed Compassionate Neighbours, made up of people who did not traditionally volunteer for the hospice. This diversity could then be seen to be important in allowing people who would not normally encounter one another to meet and explore shared experiences. The relevance of this for the project as a whole is explored further in Chapter Nine.

Power in being equals

Changed power relations were not only seen within the formal structures of the project. Two further actions outlined in Chapter Six describe how the relationships that developed between the Compassionate Neighbours themselves and with the Community Members were based upon an egalitarian sense of being peers, irrespective of differences in age, ethnicity, illness or position within the project. The themes *'Training develops new relationships not roles'* and *'A desire exists for control alongside companionship'* capture this egalitarian principle in action. Although the discovery of equal relationships between Compassionate Neighbours training together may be understood as a result of the structure of the programme, equal relationships observed between the Community Members receiving support in their home and the Compassionate Neighbours was more surprising. Compassionate Neighbours framed the relationship between themselves and the Community Member as one of equals from the outset, this being in turn influenced by the training. However, once the visits had begun, the Community Member

participated in shaping the relationship to allow their active contribution and to ultimately influence the impact of the relationship and match on both themselves and the Compassionate Neighbour. The narrative of control that ran through the experiences of Community Members will be explored in the final section in this chapter, 'A sense of agency was built'.

Power across a divide

The changed power dynamics that existed through outreach, selection and training continued into the relationship Compassionate Neighbours developed with the hospice once they had graduated. The process from Chapter Six '*Participants act with autonomy*' captures this in part, highlighting the important dimension of trust that the hospice displayed towards the Compassionate Neighbours and the way in which Compassionate Neighbours were able to utilise this to act with autonomy.

The equity seen to be underpinning and informing the relationship between the Community Members and Compassionate Neighbours also finds parallels within the hospice – Compassionate Neighbour relationship. The hospice clearly articulated through the project that the contributions of the community were valued and necessary alongside professional care, and that they relied on the community response, in order for high quality care to be provided to those who needed it. This expression of respect for the contribution of the community and for the Compassionate Neighbours themselves, both in words and actions led reinforced the sense of equity.

Whilst the hospice was seen to be giving power to the community, through the Compassionate Neighbours, the Compassionate Neighbours were observed to be taking authority in the subject of death and dying, and in the running and direction of the project itself. The giving of power and taking of authority were intimately related and interdependent. The Compassionate Neighbours were dependent on the hospice giving trust and power in overt ways such as the giving of a hospice lanyard with photo identification cards, and subtle means such as placing no restrictive boundaries about how the project could begin to adapt and evolve to local needs, and the implicit support to shape the project to meet them. In response to this, the hospice was dependent on the Compassionate Neighbours taking authority, to develop a community response to death and dying that could begin to meet the

social needs of the dying, to bring evidence of this impact back into the hospice to justify the financial and other support and to spread the message of this work in a way they were unable to in the wider community.

8.2 Relationships defined by reciprocity

The changed basis of power within all the relationships within the project allowed the expression of a further set of behaviours. The key pattern of behaviour underpinning all relationships within the Compassionate Neighbours project was reciprocity and this theme was introduced and explored in Chapter Seven. Reciprocity was most easily observed within the relationships between Compassionate Neighbours themselves. The changed power structures that informed the training were important but not the only factor. A second crucial factor was the equalising nature of death, dying, loss and care. This meant Compassionate Neighbours could relate to one another on a common level, irrespective of their differences and begin to build relationships based on shared experiences and trust. These relationships were sometimes experienced on a one-to-one basis but more often experienced as membership of a network, all of who gave and received support at different times. Reciprocity was not always directed and exchanged with the same Compassionate Neighbour; support was often given to one member of the network and received from a different member. The quality and nature of relationships between Compassionate Neighbours facilitated the building of networks of reciprocal relationships coalescing around personal and local issues of death, dying, loss and care. These networks were understood to be compassionate communities and represent an important outcome of the project as a whole, quite aside from relationships that subsequently went on to be developed with Community Members or the hospice.

The reciprocity observed between Community Members and Compassionate Neighbours had its roots in the sense of both parties existing as peers, rooted further still in their power relations. Compassionate Neighbours did not approach the relationship with the belief that they had the answer to issues the Community Member may be facing; there was not the sense that this relationship would solve social isolation for example. The Compassionate Neighbours were able to express their own needs and vulnerabilities in the relationship, an important step in developing a reciprocal basis for interaction. This meant that in many relationships,

both parties supported each other, using differing methods, dependent on their capacity. The bringing of food, the remembering of important personal details or a phone call when someone was unwell were some of the means through which both Community Members and Compassionate Neighbours were able to enact reciprocity in their relationships.

The interdependent nature of the relationship between the Compassionate Neighbours and the hospice has been described in the preceding section. This interdependence facilitated a more overt reciprocity. The hospice demonstrated pride in the Compassionate Neighbours; they were frequently featured in hospice magazines and the hospice was understood to be lending a much sought legitimacy and safety to their role as people caring for others in the community. The Compassionate Neighbours reciprocated this through their efforts to challenge the prevailing negative attitudes towards the hospice in many communities and to invite them into the hospice. This changing of local attitudes towards the hospice fostered by this reciprocal relationship had a different basis to an educational or awareness campaign about the type of services available. It instead focused on the hospice as a community resource, accessible and responsive to the local community and there to be used and shaped as they saw fit. Compassionate Neighbours felt they had insight into and control of something that others did not have access to, and that it was their duty or responsibility to share this with their wider communities.

8.3 Building a sense of agency

The changing dynamics of power and the expression of reciprocity define a new set of relationships. These relationships in turn create a new space in which people can interact, gain meaning and value in their lives and change personal circumstances and experiences. In this sense, the project did not deliver an intervention, but rather created a potential space in which people could build the skills and confidence to change their own experiences or the experiences of others. The action of the project was to remove the barriers and blocks that prevented this work and these relationships from occurring naturally, everyday between communities. There is not one impact that follows from this work; a diverse set of impacts exists for the diverse set of participants. That being said, a common pathway can be discerned through which participants achieved change. The development of agency in participants is seen as a common means through which individuals and communities are able to

gain the confidence to begin effecting change, observe the effected change, to feed this energy and reinforcement of confidence and self-efficacy back into the project and into their development of capacity.

The agency of Compassionate Neighbours was illustrated throughout the project and they represent the group with the most significant development in this respect. Compassionate Neighbours frequently joined the project profoundly socially isolated, anxious of being part of a group and lacking confidence or self esteem. This study has captured the stories of participants who felt they had undergone a personal transformation, a renewed sense of confidence, purpose, connection and energy.

Community Members also expressed this sense of agency but usually to a lesser extent. This disparity can be understood through the relative positions Compassionate Neighbours and Community Members occupied in the project. Compassionate Neighbours had the opportunity to develop multiple reciprocal relationships both with individuals and organisations and to gain personalised support in meeting their needs. Community Members had, in the main, only one new relationship through which to develop this. Many also had a limited time frame in which to develop the relationship, due to their life-limiting disease. Although this sense of agency was observed to find lesser expression in the Community Members, the fact that some were able to find opportunities to develop it at all is a significant finding and points to the opportunities to foster it in the future.

The development of agency within the project was not bound by its expression within the project. This study witnessed the agency developed by participants begin to influence wider issues within end-of-life care and beyond, into related fields such as maternity care and mental health, paid social care or in the compassion and tolerance enacted to strangers on the street. Agency can be understood as the main facilitator for impacts from the project, but the scope and nature of such impacts were wide ranging, both in place and time.

8.4 The relation of the categories

The categories outlined in this chapter can be understood to influence all aspects of the project and ultimately shaped and defined the project as a whole. They are interrelated, with the change in power relations being a necessary first step, on

which the subsequent categories could be built. The reciprocity that defined relationships sees its base in more equitable power relations and similarly it forms the basis for the development of a sense of agency. The new qualities of relationships developed throughout the project provide the space in which people can begin to influence the direction and character of their lives, and the lives of others. This space sits somewhere between the lay community and the hospice. The recognition of and enactment of control and efficacy over their lives led to renewed sense of power for participants, feeding back into the first category and setting up a reinforcing course. This leads to the expression of mutuality at all levels within the project.

8.5 Summary of chapter

This chapter has described the three themes or categories that underpin the project as a whole. They link the actions described in Chapter Six to the impacts and experiences described in Chapter Seven and are the drivers for both the conflict and synergy that was observed to take place as they found their expression within the project.

Chapter Nine: Collective social capital: a new model for new public health and end-of-life care

This chapter places the findings of this study, presented in Chapters Six, Seven and Eight in the context of the literature regarding a new public health approach to end-of-life care. It discusses these findings with particular attention to the literature relating to social capital, both in general and as it has been used and interpreted in end-of-life care. As a result of this appraisal, a new model of social capital in end-of-life care is presented. This model goes beyond existing conceptualisations of social capital to encapsulate the new understanding and perspectives afforded through this study.

9.1 A summary of the main findings of the study

This study has explored the development of a compassionate community project in the context of a hospice. In Chapter Six, the six actions that were observed to take place at the start of the project were described, through which the competing demands of a service-based approach and a community development approach were negotiated. The combination of these actions led to the project being situated simultaneously within the hospice and the community and helped define a new space for this work. In Chapter Seven, the experiences of participants were explored and these were predominantly understood to have been experienced through the new relationships built through the project. Interestingly these relationships not only existed between individual participants but also with the hospice as an entity. The impacts of the project were then illustrated, such as reduced loneliness and improved wellbeing, changed attitudes and access of the local community to the hospice, alongside wider changes relating to compassion and tolerance enacted in the wider community.

Through Chapter Eight, the underlying processes or categories driving and defining the project were articulated. These related to changing power dynamics, the expression of reciprocity and the building of agency. These three categories provide a basis for understanding the facilitating actions described in Chapter Six and go on

to explain how these actions result in the impacts and experiences that follow from involvement in the project. These categories resonate strongly with the elements of social capital, built on such concepts as trust, norms, reciprocity and connection (Onyx and Bullen, 2000). This therefore requires a deeper exploration of the emerging categories from this study in relation to these concepts from social capital. New public health identifies social capital as one of the means through which impacts of the approach are realised and thus it is important to understand what this study supports, challenges or refines in this theoretical and empirical body of knowledge.

9.2 A reintroduction to social capital

The concept of social capital in end-of-life care was introduced in the literature review in Chapter Three but this section explores the use of the concept in a more critical respect. Social capital emerged formally as a concept in the 1990s and was popularised by Putnam's 1995 article, 'Bowling Alone' (Putnam, 1995) that described the apparent decline in social capital in America. Since this publication, a substantial amount of theoretical and empirical work has developed, particularly relating to health, and social capital now represents a recognised, if contested, contributor to the support and maintenance of health and wellbeing. Three levels of social capital are understood currently; *bonding*, describing relationships between people sharing similar characteristics; *bridging*, between people across difference; and *linking*, across explicit power differentials (Woolcock and Narayan, 2000). There is an increasing body of empirical evidence supporting the association of social networks and social capital to a range of health outcomes, but significant debate remains about the way in which such impacts are mediated (Szreter and Woolcock, 2004). This link has been perceived to be so significant that some authors have called for health promotion to now focus on the nature and quality of interactions between people rather than attempting to modify individual risk factors (Baum, 2015, p. 547). However, there is increasing acknowledgement that social capital is not always a positive force and that it can have negative intended or unintended consequences (Portes, 1998). Finally, the inverse association between social deprivation or poverty and social capital has been demonstrated (Kawachi, Kennedy, Lochner, *et al.*, 1997), meaning issues of social justice and equity pervade all discussions of social capital, whether acknowledged or overlooked.

Bridging social capital

In this study, members of a local geographical community came together to participate in a project. The local area was ethnically diverse and the resulting cohorts of participants were also correspondingly diverse. This diversity and the unity that emerged from it were highlighted as one of the facilitative actions for the project in Chapter Six. Participants spoke of the richness of engaging with people 'you would not normally speak to' and of the network being stronger and richer due to the diversity within it. In social capital theory, this can be understood as bridging social capital, where new relationships are formed across difference. Authors highlight the importance of bridging being a horizontal metaphor – this describes people who are dissimilar according to a range of characteristics but are not interacting across formal power gradients (Woolcock and Narayan, 2000). The network of reciprocal relationships that were established through the Compassionate Neighbours project were observed to develop across differences such as religion, age, class, sexuality, employment status, health status and ethnicity, but participants expressed clearly that this diversity gave depth to the relationships they developed within it. Participants in Chapter Six expressed surprise at discovering a shared experience of grief and loss, a shared love of the same food or the power of being accepted for your beliefs or sexuality by someone holding different views.

The coming together of a diverse group of people on a common platform of issues relating to death, dying, loss and care created a sense of unity, shared purpose and tolerance and this was seen to provide much of the energy and motivation for the project. The diversity of the group also provided members with access to new points of view and new resources that influenced their lives; whether this was reflecting on experiences of losing one's mother or where to go for housing advice. This is a central component of bridging social capital; it provides people with the opportunity to harness the resources of other groups to meet one's own needs and in this way represents an important means by which individuals and communities can achieve social leverage and social change (Newman and Dale, 2005), something observed to be taking place in this study.

What was interesting in this study was that the generation of bridging social capital was not just evident within the group of Compassionate Neighbours trained, but also between Compassionate Neighbours and the Community Members they visited. This expression of bridging social capital relied on the shifted nature of power relationships between the participants in the project. The matched relationship was based on a principle of parity; that both parties were equal but different. This basis then allowed a mutual exchange of views, experience and support, allowing each to draw on the other's resources and build bridging social capital.

Linking social capital

Beyond the relationships between individual participants within the project, a further set of relationships developed between participants and the hospice as an organisation. As was discussed in Chapter Seven, the majority of such relationships existed between the Compassionate Neighbours and the hospice. These relationships were based on the principles of mutuality and reciprocity and were possible due to the changed power relations that operated between the participants from the community and the hospice. These relationships fall broadly under the heading linking social capital; operating across the power divide of a healthcare organisation and the people it serves (Szreter and Woolcock, 2004), but there also exist some important differences.

These differences primarily relate to the reciprocal nature of the relationship between the Compassionate Neighbours and the hospice, a characteristic that is not discussed in the literature relating to linking social capital. This led to two separate but related outcomes, based on the changing power dynamics and this expression of reciprocity. The first was that hospice practice was changed. Gradually, over the study period, practices specific to the Compassionate Neighbours project could be seen to spread to other projects within the hospice, such as to influence wider hospice volunteering practice and in other, subtle ways as the hospice interacted with the wider community. The Compassionate Neighbours project and its principles were observed to move from a peripheral to a central position within the organisation. This movement triggered both a subtle and an overt reflection on, and change in, practices relating to power, regulation and community, leading to change within the hospice as an organisation.

The second and related change was on the part of the Compassionate Neighbours and by virtue of this, the wider community. A sense of ownership and of pride developed around the hospice, in stark contrast to the initial reactions of fear and avoidance. The mutual relationship between the hospice and the Compassionate Neighbours, built on respect and trust, led to the Compassionate Neighbours, and subsequently members of the wider community, developing a sense of ownership of the organisation. Participants expressed this feeling as an acknowledgement that the hospice was there to serve them, that it was an organisation that respected them and could be trusted. It was built on a sense of investment and ownership of the organisation. It speaks to the differences between a service-recipient relationship as compared with a partnership. Compassionate Neighbours took this ownership out with them into the wider community and challenged prevailing stereotypes and preconceptions. This sense of ownership led to a range of further impacts, such as new people accessing care and changed wider community attitudes to the hospice. There were examples of people who came in to use the services of the hospice, convinced only by the words of a Compassionate Neighbour. This has important onward implications for equity of access to services for many communities.

What is different in the relationship, and as a result the social capital that developed between the hospice and Compassionate Neighbours, was the shared trust on which it was built. This shared trust could be observed to develop slowly over the study period. The hospice demonstrated trusting relationships towards the Compassionate Neighbours through material offers such as the lanyard to identify them as part of the hospice whilst out in the community, and ended with Compassionate Neighbours being invited to speak freely with commissioners, councillors and at national conferences, on behalf of the organisation. Similarly, the trust the Compassionate Neighbours expressed towards the hospice was manifest in their endorsement of it as a potentially contentious organisation both to for them to be publically affiliated with but also to urge those approaching the end of life to trust it to care for them. The development of trust, dependent on the reformed power relations could be seen to impact further on the power relations, setting up a reinforcing relationship that continually challenged and altered the relationship.

Redefining linking social capital

This study therefore critiques the existing understanding of linking social capital. It is traditionally understood in the literature as a one-way relationship; communities attempt to influence state machinery or local government, to achieve a voice in order to make services and structures more suited to their needs. The government or state bodies may or may not respond. Although there have been some descriptions of synergistic relationships between government bodies and communities from the perspective of economic models (Evans, 1996), the description of a reciprocal relationship whereby members of a community and a healthcare organisation engage in a reciprocal and mutually interdependent relationship has not been described, particularly not in an end-of-life setting. This goes beyond examples of financial dependence, noted in the literature (Gaskin, 2003), to respected relations that, through reflection and learning, change each others' perspectives, assumptions and practice. This study defines a new relationship that can exist between an institution and a lay community, allowing the community to engage with the hospice with a level of parity that did not exist before the project. This reciprocal relationship developed over a number of years. Not only was the community developing capacity and knowledge through its participation in the project, changing as a result and pressing the hospice for a more appropriate or accessible service for them, as is often observed in a project developing linking social capital, but the hospice embarked on a process of learning and reflection, challenging its staff, changing practice, putting trust in community members and exposing itself to vulnerability. It is this reciprocity and interdependence between a hospice and a community that refines existing conceptualisations of linking social capital.

9.2 Revisiting social capital in end-of-life care

The term social capital and concepts relating to it are used frequently in the new public health approach to end-of-life care literature and these perspectives will now be appraised. Kellehear (2005) introduces the concept in *Compassionate Cities*, describing the improvement of levels of social capital as one of the goals of new public health and states that when these levels are not strong, community development approaches can be used to build it (ibid, p19). Further, he goes on to acknowledge that broad debates that exist within the field but presents social capital as a resource that exists between citizens and within communities, rather than

between organisations and citizens. This position is illustrated through the somewhat polarising section titled '*Health services versus social capital*' (ibid, p48), suggesting in some way that the development of health services within end-of-life care is incompatible with the development of social capital in communities, proposing almost a sum zero game, where only one side can succeed.

Although the alignment of social capital with end-of-life care is an important first step, this presentation of social capital is relatively idealised. No mention is made of the potential harmful intended or unintended consequences of social capital and although extensive references are made to issues of exclusion and social difference (ibid, p64), the inverse relation these concepts have to social capital are not acknowledged. More recently, some authors have begun to explore the link between levels of social deprivation, social capital and social support (Lewis, DiGiacomo, Currow, *et al.*, 2014), this recognition does not form a central part of the new public health approach to end-of-life care literature.

In an attempt to explore the concept of social capital as it relates specifically to end-of-life care, Lewis and colleagues (Lewis, DiGiacomo, Luckett, *et al.*, 2012) devised a social capital framework for use in the field. They provide a detailed account of the potential negative outcomes of social capital and importantly the capacity of social capital to both increase social inclusion and exclusion at the same time. They recognise the interaction between social deprivation and availability of social capital and of the gendered nature of how social capital can be experienced, through the explicit acknowledgement of the central role power plays in social capital both in this and subsequent papers (Lewis, DiGiacomo, Currow, *et al.*, 2014). It is then interesting to see the framework the authors produce for social capital in palliative care, which appears not to incorporate these perspectives on the role of power. Bridging social capital, understood more generally to operate horizontally, across difference but not power (Woolcock and Narayan, 2000), in this framework includes relationships with other community members alongside relationships with healthcare providers. This misses the crucial acknowledgement that healthcare often operates across a power divide, particularly when issues of inequity of access operate, such as are widely acknowledged within end-of-life care (Dixon, King, Matosevic, *et al.*, 2015; Care Quality Commission, 2016). This omission of power relations can be seen in the framework as a whole, which presents a professional perspective on

how social capital can be created by professionals, rather than on how communities may build these assets themselves. The final dimension relating to macro or linking social capital mediates the relationship with the state or large organisations solely through national palliative care bodies, rather than citizens. As such, the rich discussions on power, gender, deprivation and exclusion in the text are missing from the framework, rendering it a tool merely for professionals. This may at best raise awareness of the relevance of social capital for end-of-life care but at worst risks a service-based response that could reinforce dominance of the professional response to care it paradoxically sought to change.

A substantial body of literature from the authors Leonard, Noonan and Horsfall has explicitly explored the relationship between social capital and caring in an end-of-life care context. Seeking to challenge the dominant narrative that caring is a burden and a drain on social capital they present an alternative perspective. They describe practice examples where social capital can be seen to develop from caring networks (Leonard, Horsfall and Noonan, 2010), and empirical studies supporting this hypothesis in caring networks themselves (Horsfall, Noonan and Leonard, 2012), in the wider community (Horsfall, Noonan and Leonard, 2011) and have utilised the technique of social network analysis to bring a quantitative element to the predominantly qualitative methods used to explore this question (Leonard, Horsfall and Noonan, 2013). This body of literature is a significant contribution to this field and develops it both theoretically and empirically. When interpreting these studies, it is important to note that they relate, in the main, to social networks that are naturally occurring. Some participants in the early studies were supported by a mentor, through a relationship set up by a local community hospice, but most networks, particularly in the later studies, had developed naturally around a dying person and their carer. These examples therefore can be assumed to be drawing on social capital that is already present within the community and its relationships, and represent bonded social capital in the main. They provide important insights into the role social capital plays in caring at the end of life, where it can be drawn upon as a resource, and how it can be shared or built between individuals or communities, but they do not provide perspectives on when social capital does not exist or cannot be utilised as a resource. The authors have followed an appreciative line of enquiry, focussing on when caring has gone well and in doing so present a valuable

perspective on social capital at the end of life, but one that may be supported by additional and divergent perspectives.

The availability or presence of social capital to draw on as a resource is an issue fundamental to a new public health approach to end-of-life care. Abel and colleagues (Abel, Bowra, Walter, *et al.*, 2011) recognise that it is often the lack of people available to care in a community that leads to professional carers being called in to provide this support, something that further feeds the professionalisation of care at the end of life. They outline two means by which a new public health approach can intervene to change this – one starting with the community, training volunteers to support others and a second, starting with the dying person's existing network and moving outwards to the community. They go on to describe an early practice example of the second approach, developed in Weston-super-Mare, in the UK. In this model, based on the mentorship model described above (Horsfall, Noonan and Leonard, 2012), a nurse or a volunteer undertakes a mapping exercise to map the dying person's social network and resources. A network is then mobilised around the person, drawing on these resources. This model may be ideally suited for a network-rich context, where social capital is available to be drawn on but this model may flounder when people present to such services as profoundly socially isolated, with minimal social networks to draw upon, as occurred in the present study of Compassionate Neighbours. This potential situation is noted by Abel and colleagues (2011) and the role of trained volunteers is suggested to meet these gaps.

This issue was further highlighted by McLoughlin (2017) in her review of a pilot study for a randomised control trial of a new public health intervention (McLoughlin, Rhatigan, McGilloway, *et al.*, 2015), based on broadly the same model described by Abel *et al.* (2011). Volunteers were matched with people at the end of life and their carers, tasked with mobilising the social network around them. McLoughlin (2017) reflected articulately about the issues the study had faced, most importantly with the intervention itself. They discovered that the volunteers often had great difficulty mobilising the social network around individuals referred in, as they were profoundly socially isolated. With no resources to draw on locally, and limited volunteer numbers and time, it was difficult to build the support needed. In one example, McLoughlin (*ibid*) described how the volunteer tasked with developing the network

instead became the main source of support for the dying individual, developing a close a personal relationship with the person and providing hands on care until her death, with the dying individual's son reflecting after her death that this relationship had been one of the most significant in his mother's life. Indeed, some years after the model in Weston-super-Mare had started, as described earlier (Abel et al. 2011), the model had to be redesigned as the volunteer mentors wanted more than just to organise a network and withdraw, instead they wanted to participate in an on going manner in the relationships they themselves had developed with the person at the end of life or their carer (Abel, 2015).

This issue points to the need to understand the model that is being proposed within a new public health approach, and to understand in which contexts certain models work or fail. The settings in which individuals and communities live and die are diverse and this critical review of the evidence suggests that a diverse range of models supporting a new public health approach to end-of-life care are also required, specifically ones that recognise the differential resource of, and access to, social capital. Waverijn (2017) describes how those without social relationships living in high social capital areas are not able to benefit from the high social capital surrounding them, underlining why a more critical and inclusive approach to social capital in end-of-life care is needed. These issues relate directly to the social justice concerns of deprivation and inequity. The participants in this study articulated feeling socially isolated and disconnected when joining the project, indeed many Compassionate Neighbours admitted to joining to have the opportunity to be part of a new social network. This study suggests we need to explicitly consider models that generate social capital alongside those that draw on it. To miss this crucial difference in access to social capital as a resource would act as a double disservice. Those that are currently unable to access social capital resources would find themselves further excluded by models that seek only to build on what already exists.

9.3 The limitations of social capital

This study allowed the exploration of the perspectives and experiences of people approaching the end of life. These perspectives can be difficult to obtain and have only rarely been captured in relation to a public health approach to end-of-life care (Pesut, Duggleby, Warner, *et al.*, 2018). Much of the theoretical literature from a

new public health approach to end-of-life care makes the assumption that people wish for more company and care from those familiar to them at the end of life, these perspectives are not clearly evidenced and certainly not explored in depth. Although Kellehear described the new public health approach as giving control back to the dying (Kellehear, 1999), the narratives that have developed since then focus more on the control of the local community. This is not to say that the dying are not part of the local community and members of the local community will not one day be dying people, but that there are subtle dynamics of power that must be acknowledged and addressed within this approach. Those at the end of life and those surrounding them have different perspectives, needs and capacity to meet these needs. This study has shown that those referred in to the project did not want company in any or every form, they wanted it on their terms and beyond this, they wanted control of their lives and the relationship. Indeed, a minority of Community Members did not feel this type of project met their needs and they chose to terminate the relationship. This is a valuable set of perspectives, captured from those who used the project alongside those who chose to leave. Company and new relationships will not solve some problems and a more nuanced view of those at the end of life is needed. Participation in compassionate communities can lead to life changing experiences for many at the end of life, as detailed in this study, but not for all. We must acknowledge the diversity of experience, need and preference and understand and make space for situations in which people request alternative forms of support. Control and agency are more important to some than connection and company and a new public health approach must allow for and incorporate these perspectives.

9.4 Collective social capital: the introduction of a new conceptual model

Figures 9.1 and 9.2 present the evolution and interrelation of a new term, 'collective social capital'. This term moves beyond linking social capital to incorporate the reciprocal and mutual relationships that can develop between members of a local community and a healthcare institution such as a hospice.

Figure 9.1 illustrates how collective social capital differs to linking social capital. It illustrates the traditional position from the literature in part a) where the three levels of bonding, bridging and linking social capital are displayed. The diagram illustrates bonding relationships, characterised as close relationships between similar people

and bridging relationships, developed between different groups of people. These both operate within the community and not across power differentials. The difference in power that exists between a community and a healthcare provider is illustrated using the horizontal line, with linking social capital operating across this differential. It is described as a one way relationship, through which communities attempt to draw on the resources available through such institutions. In part b), the power divide shifts to allow more equity in the relationship and the permeability of the line represents this. More relationships are possible and emerge and they become reciprocal in nature, as both community and hospice interact in a mutual and reflective way.

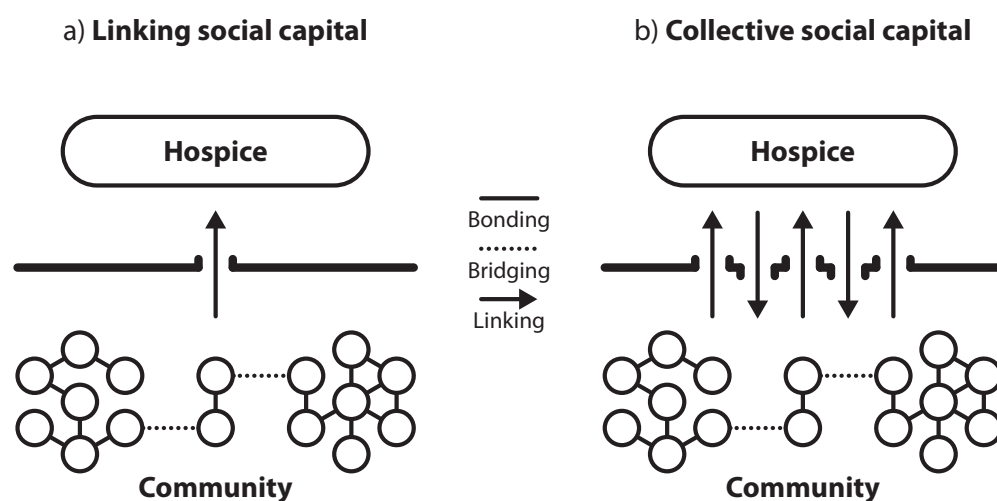


Figure 9.1 The emergence of collective social capital

The conceptual model presented in Figure 9.2 represents an integration of the key findings of this study and describes in more detail the processes taking place in part b) of Figure 9.1. It captures what takes place at the start of the project, during development and once embedded. It begins by describing the essential prerequisites for compassionate community development, specifically that existing power relationships within whichever setting the work is taking place are examined and redressed to allow for people or organisations to engage as peers. This allows people to interact in a new space where reciprocity and mutual respect is possible. This can then lead to the creation of a range of new networks throughout a community. These networks, based on realigned power dynamics, allow the

formation of both bridging social capital and collective social capital. Collective social capital can be thought of as a subsequent step beyond linking social capital. It fosters interdependence and reciprocity between communities and organisations, such that each can develop and grow, learning from one another and supporting change and improved capacity for working together in the future. Collective social capital may be defined as a set of reciprocal and interdependent relationships that exist between members of a community and an organisation when power dynamics in their relationships are addressed and a reflexive process of learning and capacity development is embarked upon. The role of changing power dynamics is situated at the base of the model to illustrate how this is often a hidden process, in comparison to the development of ownership of the hospice by the community and the engagement through universal issues, which are more visible processes.

Collective social capital, when generated alongside bridging social capital, leads to a sense of agency and control that feeds back into and further improves the challenging of existing power differentials in the community. It also leads to a new sense of ownership of the hospice, as a community resource to serve their needs. Again, this sense and feeling of entitlement and ownership allows more people to consider and reflect on the issues of death and dying, meaning more engage with it as a universal issue. Finally, these drivers lead to a series of different impacts for different stakeholders. Changes in personal indices such as wellbeing and loneliness can take place, alongside changes to the hospice and the wider community, beyond end-of-life care and relating to how tolerance and compassion are expressed and enacted. These impacts support the development of further social capital, setting up a reinforcing process.

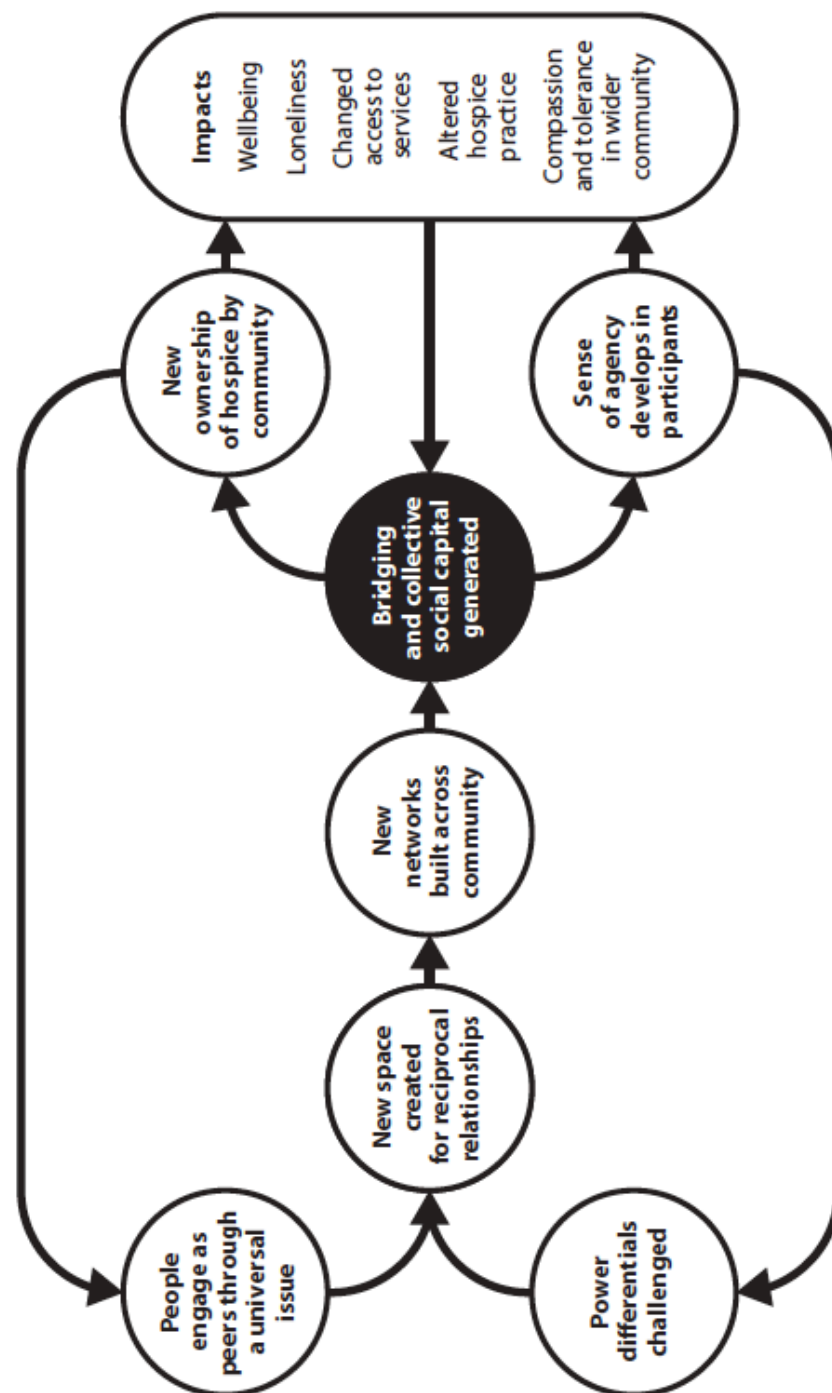


Figure 9.2 Collective social capital: a new model of social capital in end-of-life care

9.5 Wider reflections on the contribution of the conceptual model

The role of professional care in a new public health approach to end-of-life care

A new public health approach to end-of-life care has rightly concerned itself with the over-professionalisation of death, dying loss and care. It has foregrounded the role of the community and forced professionals, communities and society in general to reassess their relationship with death and their role in supporting others. In doing so, it has emphasised the role and importance of community action and the need for hospices and other professional services to step back. Whilst this has been an essential first step in order to allow community action a place at the table, an opportunity to simultaneously support, reshape and reorientate hospices and other professional services has been overlooked. The Ottawa Charter (WHO, 1986) serves as a reminder to how community action sits alongside the need to reorientate health services; all pillars are interdependent. The language of a new public health approach describes community action as augmenting professional care (Kellehear, 2005), as working alongside but potentially separately to existing services (Abel and Kellehear, 2016) and the existence of parallel siloes is well documented in the literature (Horsfall, Leonard, Noonan, *et al.*, 2013). What the new public health approach has not yet developed is a means by which hospices and other organisations can be supported to reflect on their own value and shortcomings, by inviting them on the same reflexive journey communities make through compassionate communities. This study has shown the benefits that can accrue when the struggle for more appropriate, sustainable and human care involves all those with a stake in providing it, individuals, organisations, networks; whole communities.

New public health approaches to end-of-life care and inequity

Concerns of social justice and inequity inhere within a new public health approach and run as a subtle subtext beneath all work. This study revealed two points through which the wider issues of inequity can be accessed in a new public health approach to end-of-life care. The first is inequality of access to social capital. This was reported clearly by participants at the start of the study, both by Compassionate Neighbours and those referring into the service. A difference in the availability of resources such as social capital has profound impacts on the ability of the ideals of a compassionate community to be translated into reality. Numerous models exist in the literature, built through different communities with differing resources and

contexts. A new public health approach to end-of-life care must not assume uniform community capacity or access to resources. Although it may often be there, allowing a rapid mobilisation of community assets and resources, it may often not. Compassionate communities, who hold diversity and the acknowledgement of difference as central principles, must not let this difference be ignored.

The second inequity highlighted is the inequity of access to professional end-of-life services. Many recent publications have set out the difference between certain groups in society and access to pain relief services or other aspects of professionally-led end-of-life care (Dixon, King, Matosevic, *et al.*, 2015; Care Quality Commission, 2016). The participants in this study endorsed this concern. They reported fears that developing new supports that they themselves ran would facilitate withdrawal of provision of services and lead to worse care. This concern of state withdrawal supported by a strong third sector response is not new but does represent a pressing concern for participants in this study who did not have ready access to end-of-life care services and were striving to access appropriate care. The impression put forth by a new public health approach that hospices and other services step back to allow them to take control was frightening for some participants. Of course, this must be viewed in the context of the prevailing narratives of professional expertise, dependence and a risk averse society, but it does stand as a valid concern of those who are struggling already to find services to support someone dying at home. Any experience of attempting to support a death at home demonstrates the importance of one's social network but also the importance of district nurses, general practitioners and paid social carers. The stepping back of such services could further disadvantage those currently most disadvantaged within the system. This point resonates with the caution called for by Demos in their appraisal of the future of end-of-life care services (Leadbeater and Garber, 2010) and other authors (Szreter and Woolcock, 2004).

The challenge of inequity is central to new public health approaches and this study has served to highlight two areas in which a new public health approach to end-of-life care could focus future efforts. Again, the approach that will serve the examination of such inequities is not one that focuses on just one aspect of the system. Communities and professionals should be seen as interdependent in end-of-life care. Taking one part and attempting to change it will have other, possibly

unanticipated consequences at other points in the system. A new public health approach to end-of-life care must assume an integrated perspective, where the interdependence of the many stakeholders, professional and lay, is acknowledged and leads a movement that recognises and incorporates a diversity of experiences.

Challenging the dominant narrative of social isolation

The final reflection on the implications of the new conceptual model relates to the positioning of social isolation as a dominant social narrative. Dominant narratives assume prevalence in society as they represent a dominant group's perspective. This study challenges the existing dominant narrative that older people and those at the end of life are lonely and socially isolated. Whilst many participants in this study acknowledged that they did feel lonely and socially isolated, others felt that whilst older age can be a time of isolation, they challenged the assumption that they require more company as a result. Some Community Members in this study clearly articulated that beyond company, they wished for control over their lives and things that influenced it. Dominant narratives become authoritative which means vulnerable groups are rarely able to challenge them, and older people represent a vulnerable group in this regard. This study confirmed that for many in the community, social isolation was a reality and they sought connection and meaning as a result. However, what is articulated beyond this is that company is not necessarily the single solution sought. For some a new relationship can lead to life changing experiences but for others, can serve as an intrusion. Although these views dissenting with the dominant narrative may be the minority, they deserve acknowledgement. New public health approaches to end-of-life care must incorporate this diversity of experience and perspective, understanding again that one model of compassionate communities is unlikely to meet the needs of all participants.

9.6 Summary of chapter

This chapter presents the main contribution of this study, the introduction of the new concept of collective social capital. Through a critical review of the literature on social capital and its relation to power, communities and organisations, the new concept can be seen to deliver novel perspectives on the role of reciprocity and interdependency between the lay and professional worlds. Following on from this, a number of critiques were presented for consideration, reflecting on issues of equity

and exclusion, social isolation and agency. It concludes with a call for a more integrated movement in new public health approaches to end-of-life care, requiring all those in society with a stake in death and dying to be at the table for discussions. This of course includes us all.

Chapter Ten: Final reflections and recommendations

This chapter concludes the dissertation. It first reflects on the quality and rigour of the study, moving then to consider the impacts of the study. These are described for practice relating to new public health approaches to end-of-life care, for end-of-life care in general and public health. It concludes with a final reflexive discussion, considering the interrelation of the researcher, the context, the project and participants.

10.1 An appraisal of the quality of the study

Limitations of the study

My position as a participant researcher provided both advantages and limitations to the study. I endeavoured to undertake this work reflexively, keeping a research diary, voicing concerns and sharing conflicts I experienced with supervisors and at times with study participants. This role was fixed; I could not undo the prior and public knowledge of my practice as a doctor at the organisation and of my previous involvement in and support of compassionate communities. Although this may have led to the inability of participants to express negative perspectives to me, I endeavoured to create an environment in which authentic, honest dialogue was supported, in the pursuit of learning and development of the field. I attempted to embody this culture of enquiry, openness and honesty as a researcher and feel this was reflected in the candour with which participants spoke. This position as both an insider and an outsider may also have afforded me additional insights and privileges not available to those acting as external researchers. The balance of the positive and negative factors relating to my role undoubtedly shifted in different ways throughout the course of the study and it should be read in the context of this fluctuating position of both privilege and impediment.

Further reflections relate to more practical issues. I coded the data, with only limited wider reflections on the themes with my supervisors. This is a limitation posed by the requirements of a doctoral study but nevertheless warrants consideration. The collecting of data from multiple sources and different paradigms supported the incorporation of multiple points of view. The presentation of the themes back to participants in the focus groups was an attempt to mitigate the impact this had,

through member checking but also grounding the emergent theoretical model in the lived and changing realities of participants.

A further limitation set by funding and the timing of a doctoral study was the length of the study. Data collection spanned almost three years due to the part-time nature of my degree and this afforded a longer than anticipated opportunity to capture data as the project matured. Still, in terms of new public health evaluation projects, it counts as relatively short. This is a challenge for all projects conducted within this field. Results are required to inform practice or policies, but many of the wider impacts elude capture in standard study time frames.

Finally, a reflection on the limitations imposed by the method of analysis. Grounded theory is built upon reducing the data to a collection of codes that are then built up into theory. A criticism of grounded theory studies is that they are reductionist and through the reduction of the data to a series of codes they split stories up and miss meaning in the whole. This risks developing categories untethered to their original context. I acknowledged this possible criticism from the start and endeavoured to contextualise my themes and findings throughout the narrative of the dissertation. The use of sequential interviews and multiple perspectives and data sources for the same event was an effort to contextualise themes and codes across multiple experiences and narratives. Finally, because I knew the participants well over a prolonged period of time, the codes and emerging themes and categories were contextualised for me in the wider life stories and experiences of participants. I have tried to bring this richness of context and meaning to the dissertation but will have inevitably failed to do justice to the depth and complexity of this setting.

Assessing the study against set criteria

Charmaz outlines a series of four criteria by which a grounded theory study can be assessed (Charmaz, 2014, p. 337). I will now appraise this study in accordance with these criteria. The first, credibility, asks if the data are both broad and detailed enough to support the findings of the study, whether the links between data and theory are strong and logical and whether it achieved intimate familiarity with the context. The data were embedded within the context with a high degree of intimacy. This was shown as I developed trusting relationships with the participants and as a member of the project. This represented one of the advantages of being a

participant researcher; I had insider status from the outset. I have endeavoured to make clear my thinking and to provide a map through Chapters Six, Seven and Eight, to ensure the data are both broad and detailed. I have allowed key themes to be traced from their early descriptive appearance in Chapters Six and Seven and supported the reader to see how I developed the categories in Chapter Eight.

Originality is the next criterion and this asks if the data and analysis afford new insights into the field, and of their theoretical significance. I have illustrated the wider relevance of this study for new public health approaches to end-of-life care, but also for social capital theory in general. Through the generation of a new concept to capture the new and original insights generated by this study, I have highlighted where this sits in new public health and social capital theory and practice, such that this can contribute and influence both fields as they move forward from this point.

The criterion of resonance could also be captured as the 'fit' of the study. Do participants agree with the findings, and do they offer new insights into their lives and experiences? Have assumptions been questioned and multiple perspectives been gained? The process of participants questioning the findings and emerging theoretical construction was a crucial part of developing a resonant study. In the focus groups certain themes were endorsed, some questioned, and further diversity and complexity within themes were offered. Although there were reflections and rich discussions, the core categories of reciprocity, power changes and agency were endorsed, with Compassionate Neighbours and project managers reflecting that it distilled down what the essence of the project was for them. In meetings and at presentations of these themes subsequent to the study ending, I have been surprised and heartened too see further representation of my theoretical model being played out in practice. The theme of reciprocity within the project is becoming a more acknowledged and recognised aspect of the project, rather than the hidden factor it appeared to be during my study. This demonstrates the role a research study can have on the setting when the findings are developed with participation and support from participants and help to shed light on processes they had not yet made explicit.

The final criterion is usefulness. This topic is discussed more fully in the next section where the implications and relevance for practice and research are outlined. This

study was conducted in a real world setting of a real world project. The questions I asked were of relevance for a rapidly developing but poorly evidenced field. I wanted to understand and demonstrate the impact of such approaches but also to describe the conditions in which this work can flourish or fail. I took an intentional step back, not presuming outcomes and using validated tools to measure them. Instead I adopted an open and emergent model, hoping to capture meaning and value for a range of participants and placing this together in a conceptual map for the next set of researchers to begin to measure and explore in detail. I am reminded of the old adage of the researcher who searches for his lost keys under the light of the lamppost, not because that is where he thinks he lost them, but because that is where the light is. I wished to shine a light over the broad landscape of new public health approaches to end-of-life care such that future endeavours can be rooted in the meaningful experiences of participants, rather than outcome measures selected for ease, validity or funders' interest.

10.2 Recommendations for practice

An important point to consider when reviewing implications of a study for wider practice relates to the issue of generalisability. Based in a constructivist epistemology, this study did not set out to deliver one answer or a single understanding of how compassionate communities develop or achieve impacts. It aimed to document and explore the range of experiences in a contextual nature, tethered to the richness of the specific project. However, beyond this, the study sought to begin to access the deeper processes that inform and shape the new public health approach to end-of-life care. These are not generalisable from the study in the traditional sense of the word, but instead relate to the ability of the study to illuminate assumptions or reframe existing conceptualisations of a new public health approach. This promotes reflection, discussion and ultimately potentially changed practice in contexts and situations very different to those described in this study.

On this basis, there are two key implications for practice for this study, with a range of further implications that follow. These relate to the position and role of hospices or institutions in a new public health approach to end-of-life care, and the role of power.

Although subtle, there was a general narrative within much writing regarding new public health approaches to end-of-life care that health and social care institutions such as hospices had (intentionally or unintentionally), led to the progressive professionalisation of end-of-life care and were therefore, by their very nature disempowering. They had been quietly written out of much of the theoretical perspectives and although new public health approaches emphasise the importance of the reorientation of health services, this was given limited space. However, what was interesting in practice was that hospices represented by far the most significant practice base delivering palliative care in the UK and in many other countries in the world. The literature was not always clear in how these types of approaches should proceed with such potentially conflicting underlying principles.

This study presents new and important insights for approaches developed in these settings. It describes the twofold role hospices can have in this work. The first is relatively straightforward, as a facilitator or catalyst; igniting something that exists within the community already but that is unable to be expressed due to a range of practical or functional barriers. It allowed people who would not otherwise knock on each other's doors to do just that, and then left them to develop their own relationships. This is an important and well-recognised role for organisations or community development workers in new public health approaches in general but a significant one to recognise in the new public health approaches to end-of-life care.

The second role speaks to a deeper and more integral position of hospices in the pursuit of compassionate communities. The interdependence of the hospice with the community on the journey of developing Compassionate Neighbours illustrated not only the importance of the hospice in supporting the participants and development of the project, but on the influence of the participants and the project on the hospice. This acknowledgement of the interdependence of learning, changing attitudes and the development of capacity is one of the most important findings of this study. The development of community capacity is a common goal of community development projects and a substantial literature has emerged to support it, but much less is written about the development of institutional or organisational capacity to understand, reflect and incorporate the learning and insights that they are afforded during these processes. Indeed, it seems strange to now look at a project developed between an organisation and a community and take only the

development of capacity by the community. The shifting of perspective to ask these same reflexive questions of the organisation and staff is significant, as lives are lived interdependently and health is not generated by communities or healthcare services alone. The acknowledgement of first the interdependence of community and hospice and secondly the importance of developing of reflexive attitudes by both is something both hospices, healthcare organisations, communities and all involved in a new public health approach to end-of-life care should pay heed to and hold as a central component of this work.

Following on from the redefined role of hospices within a new public health approach to end-of-life care is the central role power plays in this work. Whilst this may not be a revelation in its own right; power is acknowledged as operating wherever there are relationships, it is the acknowledgement and redressing of established power relations throughout the project, which is a key implication for practice. Shifting power dynamics was seen as one of the key founding processes through which other central actions such as reciprocity and agency could develop. The changed power relationships were seen to be operating across the project, between the Compassionate Neighbours and those they visited and also between the hospice and Compassionate Neighbours. It is the focus on the equitable power relations between Compassionate Neighbours and Community Members that draws the difference between this work and that of befriending services. A meeting of peers defines these relations, even if they take place across significant difference. This allows the expression of reciprocity and mutuality and the sustainability of a long-term friendship. It is this that leads to the outcomes observed in this study. Some befriending services may see some outcomes as have been achieved in this study, if people are negotiating the service to develop authentic relationships, but this is often done contrary to the rules and boundaries. The allowing of patients or recently bereaved people to participate and support others at the end of life was a clear example of this and one that sits apart from much standard practice in the sector. The explicit positioning of 'service provider' and 'service recipient' as equals, both giving and receiving care can seem radical when viewed through a healthcare perspective but one-way service based models will not lead to personal transformation and will not address the contemporary and multifaceted challenges of social isolation, loneliness, and care at the end of life. The challenge now stands

for hospices to incorporate this learning into social models of support that transcend befriending services and for communities to begin building these relationships.

10.3 Recommendations for research

This study has presented a new means through which social capital in end-of-life care can be understood. The next challenge entails exploring this in different contexts and settings and understanding how the components of the conceptual model shift or adapt under these new conditions. A conceptual model is an inherently reductionist tool, based on current insights, data, perspectives and contexts and must be taken with this in mind. However the value of conceptual models lie in their ability to make plain steps and concepts involved, allowing aspects or relationships to be picked up and examined. This conceptual model is presented as a call to future researchers; explore and critique this. It is intended as a first step in developing appropriate, sensitive yet rigorous empirical research into this area, placing the lived experience of participants as central. It is my hope that many revisions and further versions of this are created, leading to a deepening of our appreciation of how this works and for whom, ensuring participants and communities remain always at the centre of both practice and research endeavours.

10.4 Wider implications

Collective social capital is a term that extends and refines the existing categorisation of linking social capital, as a way of understanding the relationship between communities and those who control the services they access. Linking social capital does not enjoy the same depth of theoretical or empirical literature as the remainder of the social capital components and this study suggests it is an under explored and under conceptualised area within social capital. The relevance of this concept beyond end-of-life care remains to be seen but the principles contained within this term deserve to be explored within the field at large.

10.5 What remains unanswered in the field?

The conclusion of this study leaves me with a number of important questions I am seeking the answers to. What will happen to the cohort of Compassionate Neighbours as they begin to approach their end of life, potentially decades away for some? Will this experience have changed those experiences and if so how? What

will the project look like in a number of years? Sustainability was not a research question in this study, which focused on development and integration but this is a pressing question both for the project and the field as a whole. And finally, but in some ways most importantly, how can more Community Members be supported to participate in the project in such a way that allows them access to the same life-changing experiences, networks and resources integral to the Compassionate Neighbour narrative? If changing patterns of disease mean that those with chronic illnesses may increasingly participate in such projects, would the longer time frames allow for Community Members to begin accessing these wider outcomes? What would this model look like if situated in primary care?

Future research in this area could explore the application and relevance of the conceptual model in different settings, the development or use of validated tools to explore components of the conceptual model such as network development, agency, trust or reciprocity. Studies could follow Compassionate Neighbours over a longer time frame to understand what happens as they approach their end of life or look at changing patterns of service use whilst participating in such a project.

10.6 Final reflexive considerations

I chose to undertake a doctoral study in a field I felt I knew well, only to see the confidence and knowledge fall away as I progressed through the research process. In some ways this was a useful process, allowing me to see things more clearly but also leading me to question assumptions and premises I had taken for granted. This stance of questioning taken for granted assumptions was helpful in situating myself within the research context. I shared these concerns and reflections with the wider research group and with participants and the project. As a result they were refined and expanded and formed part of the discussions in this thesis. The voicing of tensions and concerns was an important part of my reflexive journey; making clear my views and standpoints allowed me to interact with participants, data and emerging theory authentically. Although these concerns were hard to voice publically within a discourse that is attempting to gain recognition and standing, the pursuit and exploration of these issues has helped me to develop a richer understanding and appreciation of the role such approaches play.

I conducted this research as a participant researcher and the Compassionate Neighbours and project team welcomed and embraced me. Compassionate Neighbours would frequently introduce me as 'one of us' to new members of the project, relating how I had been there since the start and that I was telling the story of Compassionate Neighbours so others could learn. In this way, my research and its utility were woven into the fabric of the project. People would often approach me in the corridors of the hospice stating that they 'had something great for my research' or bringing letters from home to elaborate on a point we had discussed in an interview or participant observation. It was important to keep in mind the role I inhabited during these discussions, making the ethical requirements of the research explicit. I found these assertions often awkward, placing a barrier between participants and myself. By being present and visible within the project and making the research an explicit, open and shared concern of the project I attempted to manage my own awkwardness whilst conforming to the ethical requirements of the study.

One of the benefits of this insider status was the trust the participants afforded to me and the eagerness with which they wished to share their stories. Although I was well known as supporting and developing the project from the start this did not restrict participants to solely positive accounts. I received numerous reflections relating to disquiet within the project, often given in a language of shared experience such as 'well, you know that's they would behave, don't you...' Through the process of theoretical sampling I actively sought out divergent perspectives, meaning they were presented alongside narratives of success. This trust and closeness developed as I had two babies during the research. Participants were nurturing and protective of me during my pregnancies and asked frequently about how my family was when I returned to work.

The research study was extended twice due to these two periods of maternity leave. The process of becoming a mother in the midst of the research will have had a range of impacts on the study and myself as a researcher, some that I am able to articulate and others I may not be aware of. One practical impact was the increased length of the study – being spaced over six rather than three years. The project developed quite slowly from the pilot project and, as with many slowly evolving

projects, many of the insights were not realised until the later maturation of the project.

Although changes in my personal world undoubtedly influenced the study in different ways, I felt also that the study influenced my personal world in turn. Reflecting on the meaning of community, relationships and compassion in local communities prompted me to reflect on my own community and the expression of compassion within it and I began to adopt behaviours locally promoted by the Compassionate Neighbours project. Acknowledging the interaction not only between researcher and participant and researcher and study, but study on researcher is important.

The process of conducting the study also led me to reflect on the role of compassion and reciprocity in clinical medicine, in healthcare encounters. Understanding what I now did about the role of reciprocity in enabling a compassionate relationship pushed me to think about the nature of the doctor-patient relationship in a formal sense. How could compassion be enacted within this relationship defined by power inequalities? After much reflection and discussion over the study period I have come to the conclusion it is in fact possible to engage in a reciprocal relationship with patients, and the Compassionate Neighbours project has illustrated this for me. A reciprocal relationship in this context is not defined by equal or equivalent exchanges or offerings, but more based in the shared recognition of humanity and of suffering, and how this can be levelling, sufficient that a patient can participate as a human being, interacting with another human being. It is the acknowledgement of the universality of suffering and of our vulnerability to this that allows this different plane of interaction. I have found in my clinical practice subsequent to concluding this study that this has been one of the lasting impacts. I have reframed my approach to the clinical encounter, supporting a shared acknowledgement of the person's suffering and issues and guiding a way forward together. This does not have to be at the expense of personal resilience or clinical expertise or care, I have found this recent practice as more grounding and allowing me to accept situations rather than working behind barriers in role and position.

10.7 Concluding remarks

This study has illustrated the interdependence of all actors in the pursuit of compassionate communities and placed power, reciprocity and agency at the heart of such approaches. This interdependence was witnessed at all levels of the project and continues when reflecting on the final relevance of the work. A new public health approach to end-of-life care was based on a requirement of end-of-life care to learn from public health. Now perhaps public health can learn from end-of-life care in the light of collective social capital. This study may have uncovered an interdependence in the relationship between the two fields too; collective social capital could have implications for areas of new public health in general, meaning public health could now be reciprocally learning from end-of-life care

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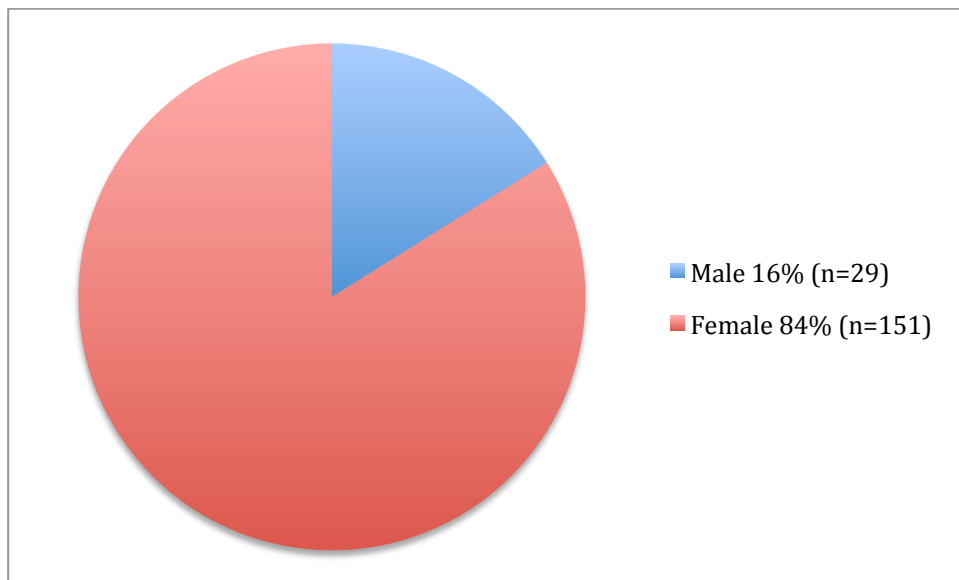
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Appendices

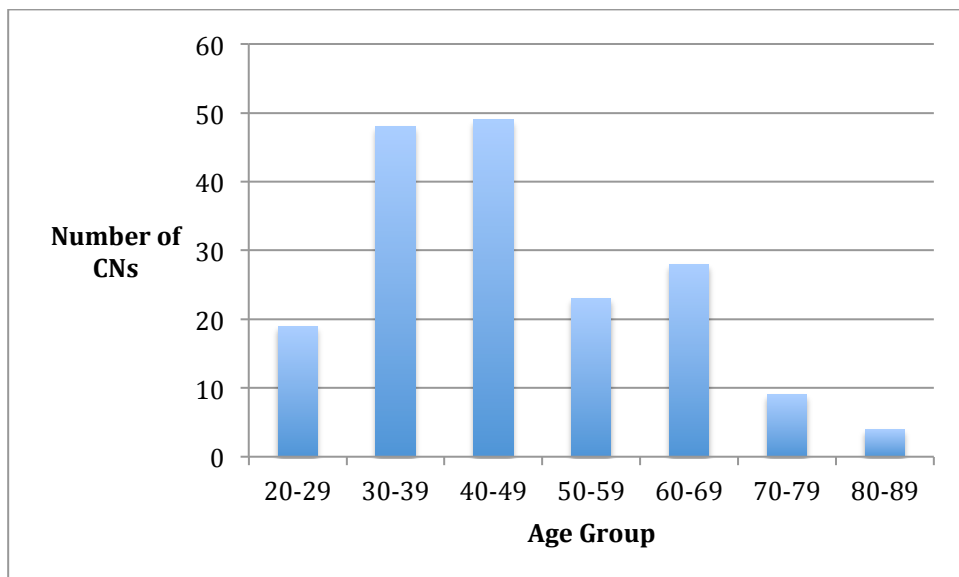
Appendix 1: Service log

A1.1 Compassionate Neighbours (n=180)

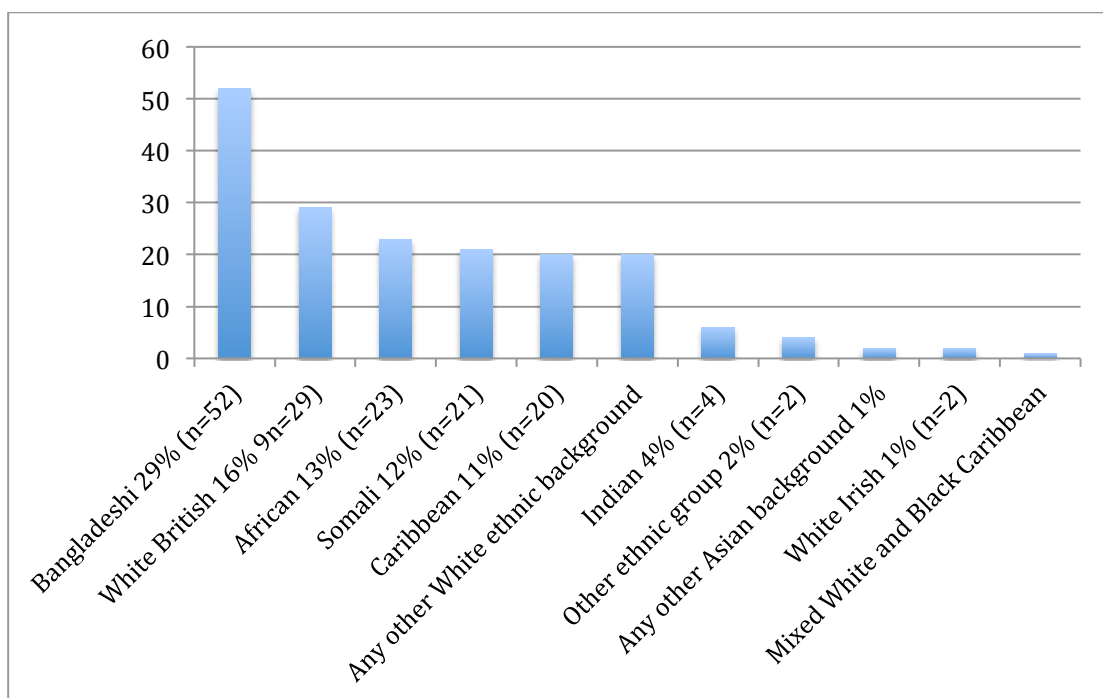
Graph1: Gender profile of Compassionate Neighbours (n=180)



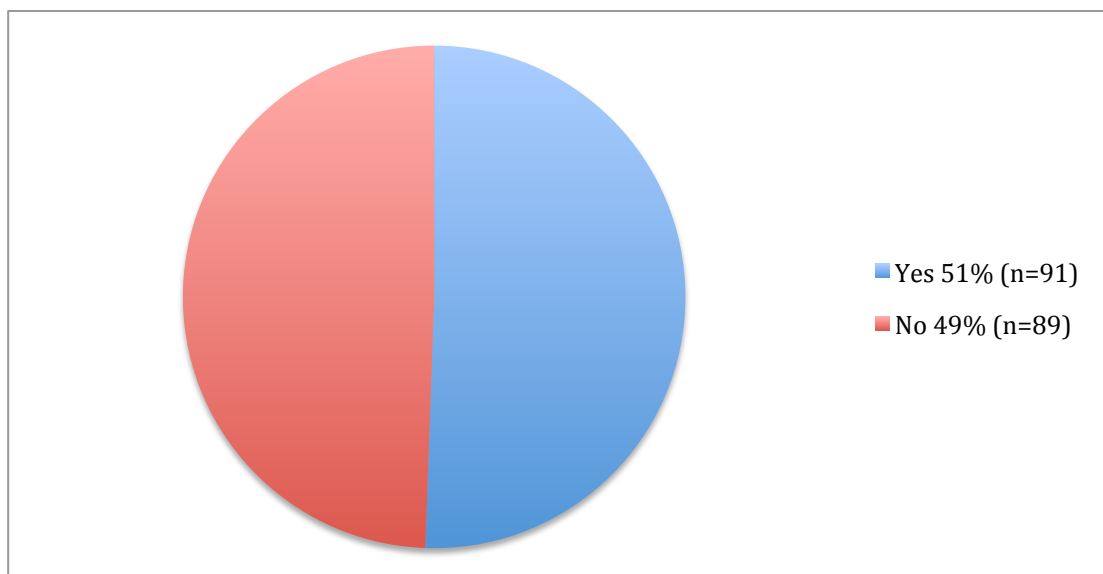
Graph 2: Age of Compassionate Neighbours (n=180)



Graph 3: Ethnicity of Compassionate Neighbours (n=180)

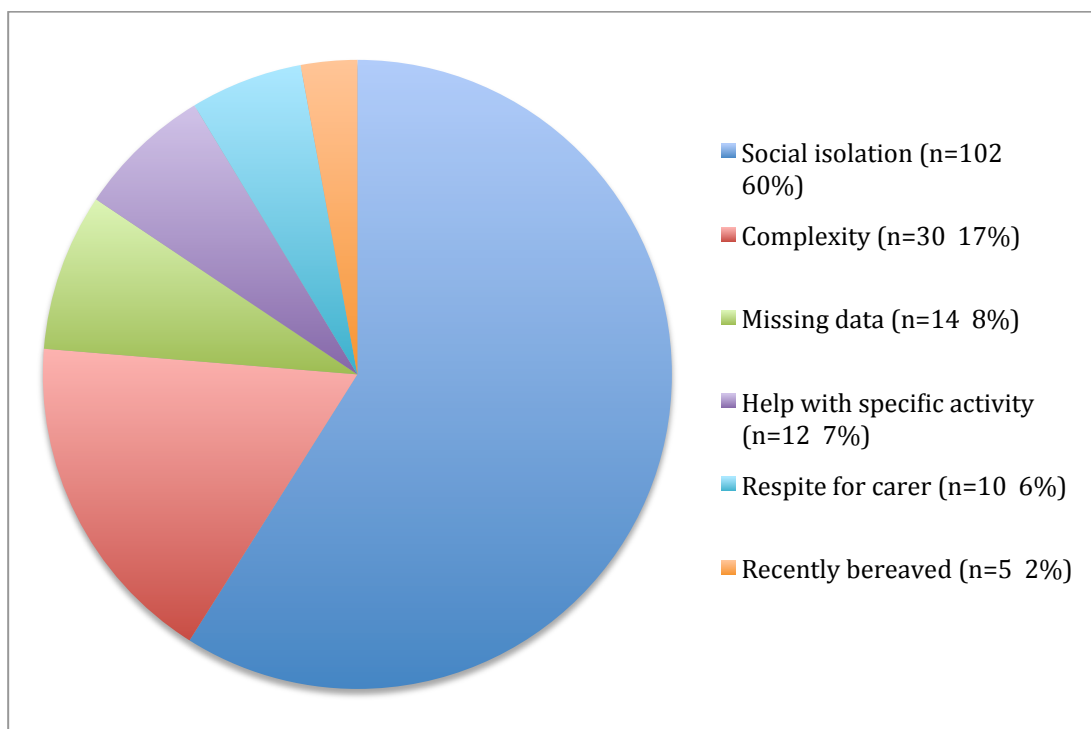


Graph 4: DBS achievement for Compassionate Neighbours (n=180)



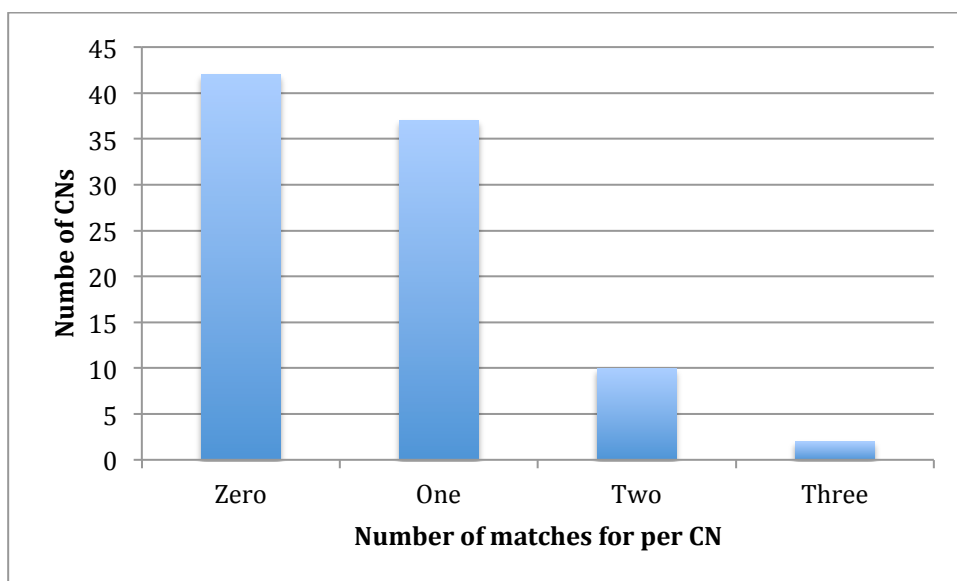
A1.2 Community Members (n=173)

Graph 5: Reasons for referral into project for Community Members (n=173)

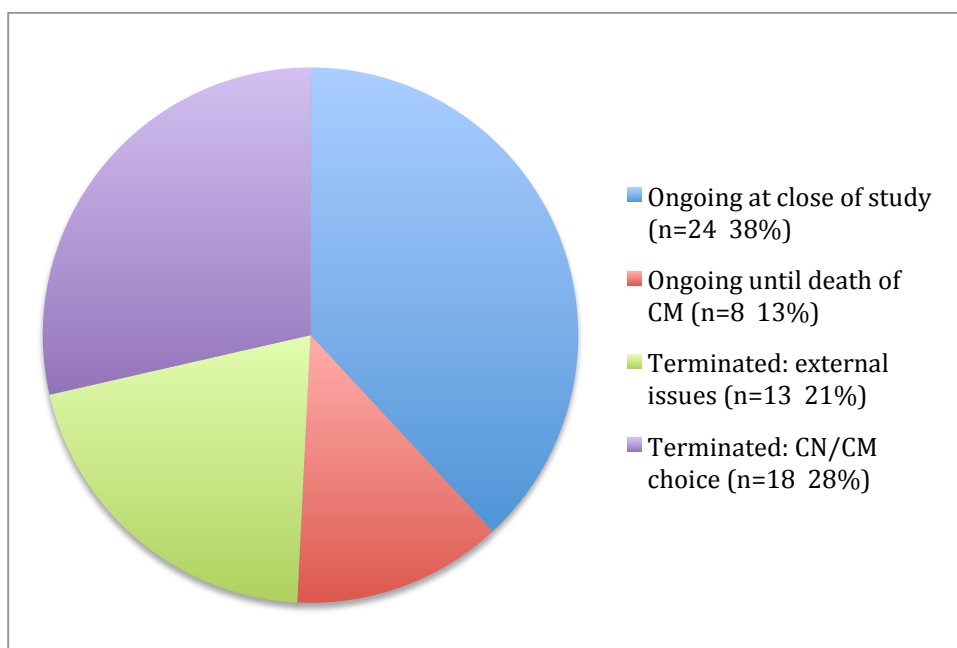


A1.3 Matches

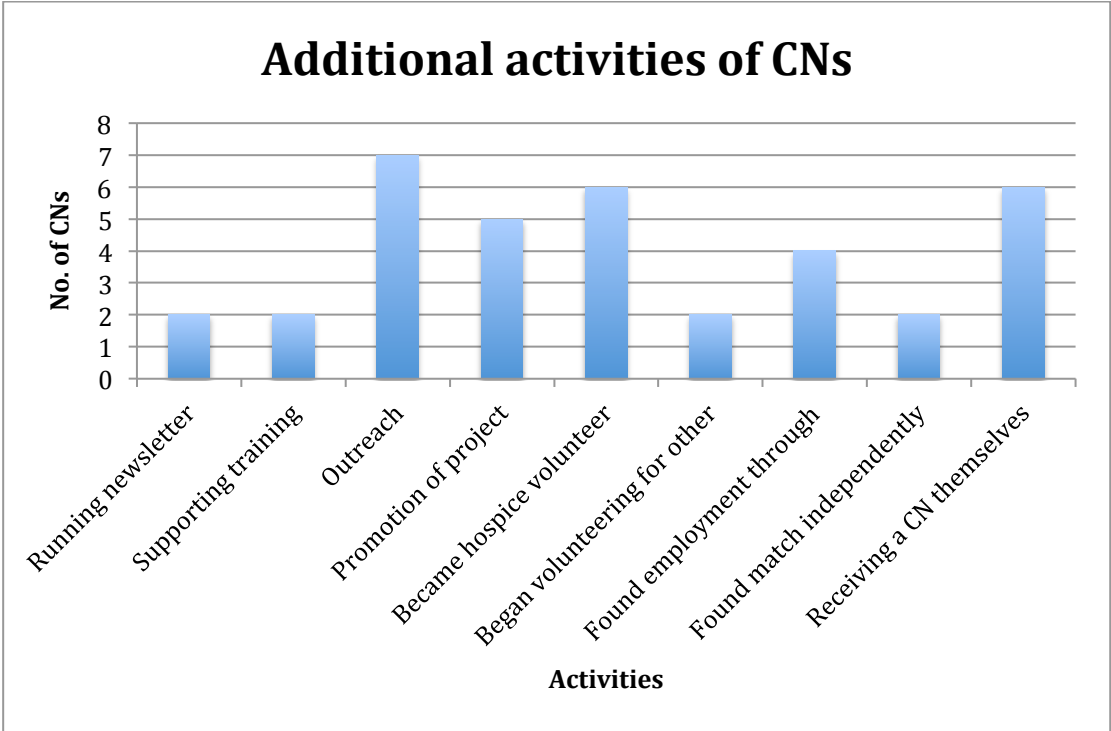
Graph 6: Number of matches per Compassionate Neighbour



Graph 7: Outcome of matches (n=63)



Graph 8: Additional activities of Compassionate Neighbours



Appendix 2: Study documents and ethical review



THE UNIVERSITY *of* EDINBURGH

CENTRE FOR POPULATION HEALTH SCIENCES

Ethics Review Group

Medical School
Teviot Place
Edinburgh EH8 9AG

Telephone 0131 650 3239
Fax 0131 650 6909
email: cphs.ethics@ed.ac.uk

15 August 2014

Dear Dr Sallnow

Re: Exploring the impact of public health approaches to end-of-life care

Thank you for resubmitting your documentation with the amendments that were requested by the CPHS ethics committee. The amendments have been judged satisfactory. I am therefore pleased to be able to inform you that the above study have been granted ethical approval.

Please be aware that this ethical approval is in respect of the protocol and methods as described in the documents submitted to the committee (with amended documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check whether this means your level 2 application form needs to be revised, and submit to the committee (via me), any documents that have been revised (study materials/protocol/level 2 form), using tracked changes. You should make clear in your covering email whether:

- (i) you are requesting ethical review of a study amendment; or
- (ii) you are not sure whether such is needed and, in the first instance, would like the committee's opinion on whether a formal approval is needed of the amended design/methods.

Yours sincerely

Lesley McGoohan

Ethics Review Group Administrator

CPHS: <http://www.cphs.mvm.ed.ac.uk/>

Ethical Review Group: <http://www.cphs.mvm.ed.ac.uk/intra/research/ethicalReview.php> (staff & PGR students only)

**Title of study**

Exploring the impact of public health approaches to end-of-life care

Introduction

My name is Libby Sallnow and I am a researcher trying to find out what happens when projects such as Compassionate Neighbours [REDACTED] are started. The project aims to support people who are caring for people with serious illnesses, by training people from their local community. We know that it is important to have a lot of support when a person is caring for someone at home but we don't know much about the type of support that is helpful or not, what happens when someone is supported and what the different people involved think. The information I get from this study will help me know how to run projects like these in the future and to understand what effect they can have on people.

Why have I been invited?

I want to understand the experiences of people who have trained as Compassionate Neighbours and who are supporting people in their community and this is why I have asked you. I would like to understand what happens when you visit the person you are supporting and how you help them. Your experiences are important to me and I would like to have the opportunity learn about them by watching what happens.

Do I have to take part?

It is up to you to decide whether or not to take part. Take time to read this leaflet, speak to family, friends and colleagues and speak to me about any questions you may have.

If you do decide to take part but change your mind later, you are free to withdraw at any time without giving a reason. You can also ask for your information to be removed at a later date.

If you decide not to take part it will not affect your legal rights, the care you may receive or your relationship with the organisations involved, now or in the future.

What will happen if I decide to take part?

If both you and carer you are supporting are interested in taking part, I will arrange to meet with you both, where you usually meet. This may be in the carer's home. You will have an opportunity to ask questions about the study and will be asked to sign a consent form. You will still be able to leave the study or ask for your information to be removed after you sign the consent form.



I will then join you for the time you spend with the carer on that day, seeing what it is like to be part of the project. You will be free to stop at any time and ask me to leave or ask for specific events or comments to be removed. I will not be recording anything, only making hand written notes.

Will my taking part in this study be kept confidential?

All the information collected about you will be kept strictly confidential. Your name will not appear on any of the information as I will give you a number instead. Only I will be able to identify you from this number and this information will be destroyed when the study is over.

What will happen to the results of the study?

The information from this study will be analysed and written up for a PhD at the University of Edinburgh. Some results will be presented at meetings and conferences attended by health and social care professionals and published in scientific journals. A summary of the results will be sent out to those who took part in the study, if they would like them. Individual people will not be identifiable from any of the published results.

Are there any benefits for me if I participate in this study?

This study may not benefit you directly, although some people do find it useful or interesting to share their views and feelings. The information we get from this study will be used to improve the services and care for people and their families who are suffering with serious or life limiting illnesses.

Are there any disadvantages or risks to me participating?

I may be observing you when you are dealing with difficult things. Some people can find this uncomfortable or upsetting. If this were to happen, you would be given the opportunity to stop the observation and given some options for some further support. You do not have to answer any question you do not want to and you can ask me not to observe certain things.

Who has reviewed this study?

This study has been reviewed by the University of Edinburgh's research ethics committee.

Who is funding the study?

The study is being funded by [REDACTED]

Who do I contact about this study?

The researcher in this study is Dr Libby Sallnow. Please feel free to contact me on [REDACTED]
[REDACTED]



If you would like to speak with someone independent about the study, please contact Dr Karen Fairhurst on 0131 650 9495 or email her at Karen.Fairhurst@ed.ac.uk.



Title of Project:

Exploring the impact of a public health approach to end-of-life care

Name of researcher

Elizabeth (Libby) Sallnow

Please tick the box beside each point below:

- ☐ I confirm that I have read and understand the Participant Information Sheet (Document 2b) dated 12/08/2014, for the above study and have had the opportunity to discuss the study with the Researcher and ask any questions.
- ☐ I understand that by agreeing to participate in the above study I will take part in a single, recorded interview discussion, lasting up to 90 minutes in duration.
- ☐ I understand that the anonymised data may be used in presentations at academic conferences or in scientific journals.
- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or my legal rights being affected in any way, now or in the future.

I agree to take part in the above study

Name of participant:

Signature:

Date:

Code of Conduct for observation of public meetings:

1. A notice will be displayed regarding the presence of a researcher and I will be easily identifiable during the meeting
2. Notes will be made regarding general events, behaviours, processes and activities and observations on the atmosphere and dynamics
3. No personal identifiable (directly or indirectly) information will be collected. No direct quotes will be taken from participants or speakers
4. When writing up the account, no reference will be made to individual participants' gender, age, ethnicity, religion or job title. Reference will be made generally about who attended the event
5. All efforts will be made to avoid indirect attribution of data. If a small number of participants belong to one ethnicity or gender and mentioning this could lead to indirect attribution, this will be omitted from the account

Appendix 3: An example of coding prompts for interviews

Prompts for semi structured interviews with Compassionate Neighbours

Introduction: research fellow at the hospice, undertaking research about projects such as compassionate neighbours and interested in how they work and the impact they can have.

Interview is designed to understand your point of view, no right or wrong answers, will take up to about an hour, but maybe more or less, you can stop at any time, skip a question or go back to things you would like to discuss in more detail.

The interview will be recorded and all the information you share with me will be kept confidential and only accessed by the research team. Anything I share will be anonymised.

I'll be making a few notes and looking at my question sheet during the interview, if that's ok?

Consent form

Any questions before we start?

Tell me about your experiences of being a compassionate neighbour.

What impact do you think it has had on you, your family/friends/community?

Why or how?

What have been the challenges?

What impact do you think it has had on your community member? Why or how?

What do you think the significance is of work like this?

Why did you sign up to this project?

Do you have any other reflections you would like to share?

Appendix 4: Sample interview transcript

Compassionate Neighbour 1 interview transcript

LS OK so this is an interview with [CN1] on xx at approximately 11 o'clock... umm... and [CN1] has read and signed the consent form and is happy to tell me about her experiences. So, [CN1] I thought we'd start just by you telling me about your experiences being a compassionate neighbour.

CN1 At the beginning I was not sure what I was coming into in regards to the training and I sort of came in an open mind, just to be there, to see and to hear and take it from there, 'cos I had no idea at the beginning of it or whatever.

LS Yes

CN1 You know about compassion but as to becoming a Compassionate Neighbour, that was a different thing for me...

LS Yes

CN1 ... on a personal level and I think part of me been there as I've experienced with my mother, who was ill and I was there for her most the time. I have got brothers but they were not available, because I was the nearest one, so anything I was called upon to go and deal with it and after I finished with it and go home, there was nobody there for me...

LS Yes

CN1 ... never had been, although my daughter was around, she had her husband and her children and I did not want to impose or put that on her. But for me, when I came home, there was nothing for me to bounce off or share that with, 'cos I live on my own...

LS Yes

CN1 ... in that context so I carried that for quite a long time and ...

LS Yes

CN1 ... I think that had put me into a part of depression at a particular time. That really depressed me and I didn't realise because of what I was carrying, it took me to a level that I didn't expect to be.

LS Yeah

CN1 ... 'cos most people see me as a strong person, so that my needs... like I didn't have any, like I can get on with it. So therefore, for myself as well, I didn't want to share it because I was protecting those I cared for but it encroached upon me and impacted me in a way that was quite awesome, you know in that sense and so therefore I went into a period of depression with that. See my doctor through the... I went to the X centre like for two weeks to have a break so I wasn't taken into hospital to be injected or whatever

LS So what's the X centre?

CN1 The X centre is for people having mental health illness, breakdowns, nervous breakdown or anything, preventing them from going into hospital to be labelled or injected or whatever have you.

LS You stay there, do you?

CN1 Yes, for two weeks. Eat, sleep and everything and you have people come to talk to you and all sorts of stuff and I had medication for a while and I took myself off it without telling my doctor [laughs]. Months I went back to her and I said 'took myself off it, I don't need it'. But just that particular time, I didn't realise how impacting it was and therefore the XX centre was on the road where my parents lived, so I had to pass there, so the memory of that was really hard to go through. So my understanding now about the need and the help that people need when they are in that rut. So that is the reason why I sort of... more or less somebody from [community development charity], X and somebody else came. X came at a particular time to speak about death, how [certain ethnicities] deal with death, in order to gear us into the compassionate neighbours.

LS That was X?

CN1 Yes, that was X. X came at one point and X came. But X's idea at the time was about umm how we deal with death and [ethnicity] have own ways...

LS Right

CN1 ... yeah ... of dealing with death, so that was beginning to open me out in a way that, oh I need to ... [sighs] because for me, the hospice meant

something totally different, a dead end place. In my mind its death, and death and death. And most people I meet now, they have the same idea that's still embedded, so it's for me now to give people different set up about the hospice because of being part of, yeah, being part of it so I'm able to enable people to see or take on a different view. I don't like my voice being on tape like that [laughs]. I hate my voice!! I know its only for your stuff.

LS Yes, it's for my ears only.

CN1 So, that's the grounding for me, that I needed to come in and to see what's going on here and during the course of the being on the course, it begin to tear away my idea and my preconceived ideas of what hospice means and it takes me on to a wider level because the person that I visit now, her ideas about the hospice was the same thing, and where she came from, she said to me, it's like you don't speak about this, it's in a whisper.

LS Hmmm

CN1 So, her view on that has changed. But I didn't speak to her about what I thought about it, I didn't say that to her because I didn't want that ... yeah. So low and behold she used to come here once a fortnight until I said to her, oh, I've been looking at the [*hospice activity*] going on and she said 'Oh, I've been involved in that', and then I saw the opening and she allowed me to know that she comes here once a fortnight, and the [*hospice activity*] is part of where she's at, you know, so I sort of, umm, stay back and listen to where people are at and if they say something about the hospice, I'll say, is that your experience or someone said that to you, or what do you personally, yeah, so I'm able to break down the barriers in a way, and enforcing my ideas but see where they're at and take it from there.

So ... (laughs)

LS Interesting, so that was how you came into being involved...

CN1 Yes, out of curiosity as well, because I have experienced what it is like to not to have...

LS Yes

CN1 I didn't know, within that ball of wool that I had, where I would fit in

LS Yeah

CN1 Curiosity as well as wanting to know as well as having within me the need and the caring bit that I would love to help somebody but it was in a tied up bundle, as it were.

LS Yes

CN1 So, the quest begin to open up that bundle and put everything into perspective, 'cos I think I could compartmentalise it and make it a whole thing, rather than bitty, bitty, bitty. So it came together.

LS It came together coming to the compassionate neighbours training?

CN1 Yes, yes, it came together in a way that, 'hold on, you've had that but this is what's happening and your idea of what is was, that was ok, that was where you were at, but now, seated as it is, so, yeah ... I don't know where it was that I got the idea about it being a dead-end place, I don't know. I can't say to you because somebody told me or whatever. It's not a hospital, it's just...

LS Yes

CN1 Yes

LS So what do you think happened when you started doing the training, as it was over about 10 weeks or so, wasn't it.

CN1 It afforded me the time and space to look at things differently, beginning with myself. If I was in a situation that I needed help and support, would I refuse or accept or prepare to hear and see where and what was offering. And then I began to think of the word 'compassion', what is it about? One of the things that came to me at a particular time is that it is an offering, and if you are offering somebody something, they can take it, refuse it or come back to it later. They might not accept it now but can you hold it for me, I might come at a week or two, or they might never come back. So I begin to look at it in a totally different way, because I'm offering myself, not offering money, I'm offering time and that, so people can pick, choose or refuse. So, beyond the offering, it's up to people to draw or withdraw, so that was the level that I begin to see it in a way... yeah, 'cos we all offer things differently. Some people offer time, some people can write, some people can ... do all sorts. What is the need? And if I can offer myself first, my presenting self,

however it is, and people can see it and take it on board. A might not take it, but B might take it, or that A might tell C and D, 'oh somebody said this to me and I didn't want it but you might fit in, so as long as it's there, somebody can feel off of it, or pass it around in that sense. It's almost the idea of putting up a bird feeder, isn't it...

LS Yes...

CN1 Different birds will come and pick what belongs to them

LS ... different things

CN1 Yeah, so ... and I think that all from so far, I've seen the training that we've had affecting each one of us in different ways. That it began with us first. Most of us, because of the timing, was done on the length of time before anything happened...

LS Yes

CN1 Our lives changed in different ways, so we became... lot of us needed the offering ourselves, the compassion.

LS You needed it personally?

CN1 Personally, yes. Even within the setting, where we go away from the week and we come back in, things happen in our lives that are not planned for, or whatever in different ways, then still some are able to come back and pool back, so the space and the time is, it's an amazing thing, you know. Its over to us first, we are the first partakers of what we are going to give to someone. It's almost like I'm on this side of the door today, because I'm here with you, somebody might be at that side, and who knows when the exchange is gonna happen, it's like that.

LS So you think that whilst being trained in the training, you were also getting something from it?

CN1 Absolutely, and also as well as giving something by sharing what's going on, what we think of what's coming from the training, our experiences out there, with people and whatever and how we present now or not, 'cos sometimes it can be negative to feed into 'oh, hospice and blah blah' and so you be part of the chain that is negative but there is no need for that to happen. Where I'm concerned, my own personal experience, now, yeah.

LS And what do you think you have got personally, from the training?

CN1 I learnt about my own strengths and my own weaknesses and I've learnt about people and how to accommodate people and I think one of the greatest parts for me was the learning to listen and hear, and slow down. 'Cos I'm a person that can go very fast, even in my speaking, sometime I have to think slow down [laughs].

LS [laughs]

CN1 Seriously! 'Cos I can blub-blub-blub very fast and you might not hear me or whatever. And because we had the training with the Turkish people, I had to really absolutely be silent to let them go through, and that was a tremendous, tremendous learning experience to be able to stop, someone else is... and they need their ... they're not the level where you're speaking your English but their language, and their language is meaningful to them and they're saying something that makes no sense to me, but to them it makes every sense. And therefore, the English to them must be just the same, so I've seen it from both sides, so it affords me the privilege of being able to be, 'cos I've never been in a setting like this, whereby you have to 'Hello, someone else need to be heard'.

LS Yes

CN1 That's very important. And it's an amazing thing to know that the Turkish community that we trained with have the same feeling and experience and negative ideas of hospice.

LS Yes, absolutely

CN1 It's an amazing thing. Although culturally different, culturally aware, living in the same country, same boundary, same borough, yet ... yeah...

LS So tell me a bit more about what you learnt... you mentioned your strengths and your weaknesses.

CN1 Timekeeping [laughs] – that is important to me. And that's why it is frustrating for me when people come in late. But I have to be silent and accommodate, 'cos I don't know what goes on, somebody might be coming on the bus. Yeah, teach me to be patient and umm [laughs] listen and not

judge, 'cos it's easy to judge when someone says something within the...
and want to correct and feel...

LS Hmmm

CN1 You know, but you have to learn to 'strum' [mouths mouth shut]
[laughs]

LS [laughs]

CN1 Or maybe outside after, somebody will come to you and say something and you say, oh, you know you said that, I didn't get it, but I didn't want to say at the time, I didn't want to embarrass.

LS Yeah

CN1 You know these little, umm, I can't find the word at the moment to say, you know certain things... Oh ... Sometimes I might have got it wrong, maybe they mean it the other way. So I have to work out, process, quick process, 'cos my mind flip over very quickly, I think very fast, 'cos one word might be said here, but I'm ten paces ahead. So I have to really slow down, accommodate other people and not be forceful. Even sometimes when I there's a point and I want to ... I have to, you know, allow other people to... Those are some of my strengths and weaknesses, entwined within that, so I have to learn to accommodate, 'cos I think very fast [laughs]. So I have to learn to ...

LS Yes

CN1 ... blend in, it's not about me, it's together as a team that makes the whole so, I have to, say, deny myself, subject myself to what is on there, rather than ... it's like see with my eyes and hear with my ears but allow them to see with their own eyes and hear with their own, it's like that sort of situation. But then later on if we meet together and somebody say something and so we can ... but not in the open at that point, 'cos I didn't want to offend or to make somebody feel less ... so these are some of the things I had to learn...

LS Yeah

CN1 ... about me, in the silence without saying anything to anyone in that way, yeah. People judge for themselves. But if we are in a setting where four

of us have to discuss and share views, ideas, keep it still at a level so that ...
yeah... fool wears a professor' hat... [laughs]

LS [laughs]

CN1 So it's in those ways, and I know that will take me into somebody's home or environment, where it is their domain, to withhold and allow the person their personal space to ask permission if certain, can do or not do. 'Cos I'll give you an example, yesterday, the person that I visited, she's not well at all, and I saw her, not looking well at all and then she told me that she got the phone call that she's anaemic. So I made a juice for her, she asked me to make a juice, and I noticed that she didn't have sufficient, so I said, 'oh, how are you going to cope, because you're not feeling too well and you need to have some blood transfusion', because of the anaemia. And her son, is he coming tonight, she said 'no'. How are you going to cook, she said I haven't got enough food, but somebody, a friend is going to shop for her on Friday, one of the persons that live within the unit. I said, until Friday, how are you going to cope? She's got enough there. Where's your son, 'cos he normally come, but he's the son that had the throat cancer and he's in bed for the week, not well.

LS Right...

CN1 So she wanted some tonic water and a friend came to get it but she couldn't get it at Tesco's, I said, I'll get it, I'll go over to the shop and get it for you, she said are you sure, I said yes. So she gave me £3 and I said I'll bring you a receipt and I got two, so it came up to £2.98. And I came back and gave her... No, no, no, I'm trying to show how it changes from the intention of what to do or not to...

LS Yes

CN1 ... and she's poorly, on continuous oxygen, so when I came back I gave it to her, 'cos I says to her, I can see the heart of you as a mother, reaching out to your son, who is not well and is in bed and I can see the tears welling up inside of you and I said to her, 'I'm here for you, if you want to cry, let go, let go and let it flow' and she started bursting, you know one month of

tears, ... she ... this lady's 82 years of age, she's crying, crying, crying, she cried and she's crying. I said let [unclear] in the bible 'let it flow' and she cried and she cried. When she finished she said, I'm feeling sorry for myself, I said no, no, no, you've got a very strong constitution because what you've been through and where you're at now, and for your age, 'cos at one point she said I don't want to continue, I said, please don't give up, you've got a strong constitution, it's just things are impacting you at the moment and believe you me, I left on a good note, leave her there feeling that she was able to ... you know, just cry, just release herself. I sat on the chair over there, she sat there [motioning to a distance between two chairs] but you know she burst out into tears, I'm telling you, and that was a tremendous thing, and simple as that, it's in her own place, her own space, but I said I can see, if you need to, please do, I'm here for you. And she ... But the relationship has been built up over because she was able to share things with me, show me her chest with the open heart surgery...

LS Yeah

CN1 ... over the weeks. So, from what I've learnt in the training, and how to present myself, how to be appreciative, how all that, it came to this point, 'cos this our number seven visit, where she just flowed, you know, it's a tremendous ... this put me in a position of my, my, my how the need is needed, how it is needful for people, although she's got her family and so forth, I'm not emotionally involved with her in that context so she is able to flow out, even when she was telling me about the death of her husband's, her son's daughter, the post-mortem hasn't come through yet in October, but she told me, she said, 'I think I know the reason she died', so for somebody to share those ... and she would not share those with the family, you know, so that was something tremendous. And she was telling me about X, Mr X. And I said, I know Mr X, I met him.

LS Who's Mr X?

CN1 The owner of X, who owned X

LS Originally? I see.

CN1 Yes. And she said to me she was working in a family bakery, but in the office, and he used to come strut around with his henchmen because when the lady said she did not get the drink from X, she said, 'don't tell me about X...' (laughs). Then she proceeded to tell me about X. And I said I met him opening, he used to sell in a wheelbarrow in X Street and when he opened the first X. But she said he would not pay the staff, wouldn't pay the bakery and the bakery closed down, so she's got nothing good about X...

LS Wow

CN1 ... in that sense, you know so. Just, just being present and the need for this Compassionate Neighbours training and the branching out, tremendous, tremendous.

LS Tell me a bit about your client, how you met, what your first visits were like and how it started.

CN1 Umm, X, who interviewed her, she heard about through umm, I think, I'm not sure, I think there is a ... I'm not sure the details as per se but she told me she had a match for me and lo and behold, the person has the same name as myself, her surname is that of my daughter, my sister-in-law before she married my brother, so, and, when we went in with X the first time, she had her television on and was impressed me, was the first thing she did, she flicked off the television, just like that. It was a rainy day, I had my boots on. I came to the door and I said, 'oh, I don't want to walk in' so bless her, she could not bend down, so she just kicked the mat for me to wipe my feet and open posture, very much accommodating, from that time. Something within us just clicked. You know and because I am interested in art, she's telling me about sewing and different things and so forth. She said, [CN1], look behind there on the table, there's a little t-shirt for a child, she said a neighbour asked her to sew it, you know she said, have a look at it, around the border, where the piping came off. She said, I have not got the energy now, I just cannot do it now. I don't know when I'm going to do it. But to be personally, with these little things, not meeting me. She told me and X to go into her bedroom and see her bed and 'cos what she'd made, ah the quilt, you know the patchwork, that's what she is interested in, she said to me you know I've

got some patterns, later on when we are ready we can do some patterns. So from day one, day one, day one, so it has been. But yesterday now, because I'm concerned of how she's not looking too well, I've asked her, 'where's your alarm system?' It was in the bedroom, I said, 'may I advise you to keep it near to you, because it's easier to press it than to try to dial 999 if you're not feeling well.' She sent me to the bedroom to get it and I placed it beside her, you know, on her table, so it's that little thing that we had but it built up over the weeks..

LS Yeah...

CN1 ... you know and she looks forward to seeing me, 'cos from that week then three weeks after she was here and then I phone in the morning, check how she is, does she want to see me? No matter how sick she is, she still wants me to come. So the phone call goes through X, I don't have phone contact with her and so that's how it proceeds. So I make sure every week at that given time I see her as I know she's looking forward to that.

LS So X arranges the time for you to go and see her?

CN1 No, the first time after we had the um the PDM meeting here and X and I went together...

LS You went together

CN1 And since then I would say to that person I'm coming at three o'clock. X will ring before to see if you're ok and if its ok for me to visit, it goes through to X. That's how it's been working and its very good, very very good. I said to X, you're a good match-maker [laughs].

LS And what kind of impact do you think it has given her, you've given me lots of examples but what do you think it means to her?

CN1 It's a kind of loving-caring one because one time she says to me, 'your hair, it interests me and impresses me' and that sort of level, you know. And one time I met her and the warden came into her place and the warden was speaking with her and met me for the first time. X got a lot of her umm contacts through the warden and the warden said to me one time, 'oh, I'm going to do a project and I want you...!' [laughs]. I'll tell you a bit what I've learned, the warden was saying to that particular person that I visited that

another person within the unit used to have a carer and they've changed over and she does not like the change and that particular person is blind and so that person like to hear voice and she's saying to that person that came, the change, 'can you speak, I need to hear you' and that person's saying, 'I'm not here for talking'. So that really put in my mind now, if I was to change from that person now, because we've established seven weeks down the line and to suddenly change with somebody, how would she feel? So maybe at the initial stages then, two persons, you have a buddy system, could be introduced at that time, that when A is unable to attend, so it, you have that going, otherwise if you suddenly take away and replace, that can have another impact and especially when this particular person's quite ill, and used to me already by sending me to the bedroom, to fridge to make drink for her, I bring the drink to the table, where she's sitting, put the amount in a glass and say 'is that amount ok', before I add the, you know and so I work with her in that context. Even if I'm there and a phone call come through, she will say 'I'll ring you later', so she holds this time sacred. So, I can understand that some people will take the change bad and ok but it needs to be worked together rather than suddenly [claps hands] so god forbid I'm unable to or sickness or emergency or whatever, that person's already known they have that rather than suddenly now a body comes in when

LS Yes

CN1 For her it wouldn't... because little things she shares with me, like she's got a sore bottom. Yesterday she said to me the doctors gave her cream, she will tell me this, I say, can you reach to, she said no, I'm going to sit on the toilet and apply the cream and you know and she will tell me how they make her bed and it is not made good, but the cleaner will do it good for her. Those are the... which is important to her, because she said I do not like the bed which is crumpled up, she sheets, she irons, the woman who irons, I said to her, 'ironing...hmmm!' [laughs] not me! But a person will do it for her. She told me that she bought the place, she gives me details about everything and sometimes people phone her, where she used to live and say 'somebody else has bought your house', keep her updates, you know, you

know. Little important things she gave me her ipad with her daughter-in-law, she's forty something, baby in her tummy, you know she showed me the picture of her dead granddaughter and the funeral and all those details, she shared with me, that is something sacred. And to just to swap over the change, I don't think this particular person will find this easy so I think at the initial stages, it need to be done at that point, even if it's not done on day one, in week three, we could introduce the person that will work with AB in case something happens but I don't think that gap should be missed. She looks forward to this.

LS Yes

CN1 She looks forward to it, very, very much, because it bridges, because although she's in a warden controlled, she's in her own place and the warden doesn't have to come around, so she does her own cooking and her own stuff in that way so its very... Just being there, not to be busy, washing or cleaning or whatever, just sitting there for that person to release herself. It's tremendous and I see the difference between that and the cleaner and the carer

LS Yes, what your role is

CN1 Yes, absolutely. But it doesn't mean like making her juice, or going to the shop or picking up something that you can't do. Before it was sort of thought differently. If you were in someone's home and they wanted you to... that would be unkind not to... you know...

LS not to help them

CN1 Not to help, yeah, yeah. I wouldn't lift or anything, she's able to drag her feet and stuff and so forth and stuff but just being there so she can say 'oh, I'm feeling poorly or I'm feeling sorry for myself' and those sort of stuff. And last week she broke her dentures and she was able to say to me, you know, crying about, she said I paid four thousand and she gave me the speil about Harley Street, but it's fixed now. Somebody came in and I said 'what, did you have to pay extra?' She said 'No, after paid four thousand!' [laughs] 'You must be joking'. So these little, you know, to share.

LS So it seems you are not there to do a practical task, it's something completely different

CN1 No, different, yes

LS And that's special

CN1 But if you've got to pick up a slipper and hand it to her, that's fine. But for her just to be there. Sometimes she say, 'I'm talking too much, you talk to me, you tell me about you, how did your week go?' Tremendous, tremendous.

LS Hmm

CN1 So that's what the learning, the teaching affords me. And I think in a lot of sense, the practice informs the theory, really, because you can't just go there and not do and in the context of having a buddy system, that needs to be introduced so, I see it in a different way. The paper says this but in practicality, each person need different. Somebody might be ok just to swap over because you might not hit it off with the person but because I've got that rapport established with her, that wouldn't be nice to suddenly... but for somebody else that wouldn't matter. Each individual case, one has to take it as it's needed. Hmmm, yeah.

LS So what kind of impact it's had on you? As a person, and as a Compassionate Neighbour?

CN1 I think the caring side of me, because I'm a mother and a grandmother and that's a different, because that's sort of family and friends that you know, but a complete stranger, all of these put together in a different way. But I have to see this individual as her own person in her own right and connect with her in some way, shape or form. And I think I've connected with her, I think my presenting self and how she is and [pauses] I can't find the words at the moment and maybe it doesn't have to have words, but maybe the spirit of the person connects with mine, something there that's come about that keep us together. This person is away from X, which is an isolated village, not knowing and in X, the place of X where it's diverse and an X year old person who is set in her ways but still open to, and accommodate that person into your home, it says a lot, it says a lot, the richness and there are somewhat similarities, when illness or something like that hits, it's almost like

all those things doesn't matter, or if it matters, it begins to pale into insignificance, if you get what I'm saying...

LS Yes

CN1 If we make it a mountain, it becomes a mountain but if we begin to break that down, we can become acceptable and normal and work within the confines of wherever, because she's very much confined, but she could still... In her sickness and how she is, she could have been brutal, she could have been nasty, 'cos some people are and behave. But this is quite a dignified, a precious, a sweet person, with all that she's gone through, there's no bitterness, when she laughs, her face just lights up like, wow, it's that sort of... she's a sweet, and I'm not saying it in a patronising, 'cos when somebody is ill, the spirit of that person come out, one way or the other, so, there is something there that words cannot describe but it is there. It just comes to you, it just comes to you and I can't, there's no point trying to pick a word out of the air, the word is not there, it's just, it's just [pauses] there. 'Cos even when I went out yesterday, she says to me 'take my keys', a bunch of keys so when I come through the gate, come on. And when I'm going your keys are there. So for someone to entrust you with that and she's got her faculties, she's not stupid or anything like that but to feel comfortable with that, that tells me the need and the impact that I have and she have on me to trust and that trust is not words to say I trust you or whatever, it's just there.

LS in action

CN1 Yes, yes, so. I have not come to any conclusions as it still a continuity of what is happening there but it's just there, it's just there. It tells me what compassionate neighbours are doing and the training and it's needful and it need to be widened to the wider, open it out to as many people as need to

LS Hmm

CN1 ... care and be partakers but the training is important, because you're training yourself as well as ... not a matter of going into a person's home and dominate or feel or think, you know. 'Cos where I speak, I would say 'I sense' or 'can I say', or 'is it ok', my language change, different when I'm at home with my grandchildren or they come to me, I would say, 'you know you're not

supposed to do that' or 'are you thinking, can you choose right?'. So it's amazing from 7 and 6 year old to an 82 year old, [laughs] so within my life or whatever, learnt the language different, but you have to keep each [gestures]

LS yes, these different roles that you've got

CN1 Yes, 'cos it's easy to want to treat her as a child and so I have to know the difference and keep each in its own compartment, as it were. It's all part of the process in my thinking, my action and whatever. And so the training is imperative.

LS Yeah

CN1 It is a foundation. Because if you don't have the foundation it will crumble. So the foundation of training is important to equip.

LS What do you think...

CN1 I've said a lot of rubbish...! [laughs]

LS Not at all. So you think the training and you taking on someone, do you think that's had an impact on how you relate with other people?

CN1 Absolutely...

LS Your family or your community?

CN1 Absolutely, on Sunday I saw a lady and obviously she wasn't well, after I dropped the grandchildren off and I had my trolley, going to Foresight meeting, I see this lady walking down the street, half dressed and whatever, she had her cigarette in her mouth and I have this smile on my face and I said 'good morning' and she went 'hello, good morning'. So even that tells you something, some people, just meandering and just say good morning and that. I just said 'hello, good morning' and she shocked. So that takes on a different... and I look at people and I see things in different ways, I begin to see. 'Cos you know even when we were training about learning to draw and look at things, so I'm observing more and my heart is at a different place. Whereas before sometimes just [clicks tongue], not to everybody but just to be selective in my mind I'm thinking 'why's that person like that or whatever'... Somebody's child, somebody's daughter, something has happened in life that has brought them to this point. So...

LS So has it changed your views of community or society?

CN1 Yes, yes, absolutely. And [laughs] 'cos I'm doing Mondays now at the X Centre, young people, training us to do the computer and the internet and they were sort of training 'old people' and I said 'who you calling old' would you call your mum or you're nan old in that way? No, we're senior citizens [laughs]

LS [laughs]

CN1 So for my own self, do you get the point?

LS Yes

CN1 It's amazing. And they're cracking up laughing. What would your mum think if she came in here and heard you saying that to us? They cracked up, they were laughing, they said 'true you know, we never thought of it that way'. I said when you say like 'old people' in that context, it's like you put us on the rubbish heap and we're no longer but there's more similarity between us than difference. And in come a group of school children who want to interview us, it was brilliant. So that takes me on a wider, within the community.

LS So do you think that starting volunteering with compassionate neighbours has led to lots of other volunteering...

CN1 Oh, absolutely, absolutely

LS Tell me about some of those

CN1 Um, [community development organisation] is one of the greatest one, like on Tuesdays I sit among the people with mental health illness and they see me, they come and call me 'aunty X', some call me 'X' that sort of level, so I'm not afraid of sitting among the people.

LS People with mental health problems who come in as a drop-in?

CN1 Yes, drop-in on a Tuesday and these are the ones I cook for and some that come off the streets so, getting to know you. Sometimes I'm walking down the street and they would say 'hi X, how are you?' It's on that level, so it opens me into a wider connection and then I go, now, to um X Church, X on the singing group, and quite a few of them, they're people off the street, 'cos on Wednesdays now they have their dinner, you know so all that fits into the scheme of things, it's like this patchwork as it were, with the different...

LS And why do you think starting volunteering with one thing led to all that? Why do you think that led to that change?

CN1 I think because in life we're all in this chain, I see that loop in the X, we're in this loop but sometimes we don't recognise it or we think we're better than being in this, in this, place at this particular time but we don't know, we don't know. So, we're in the scheme of life [laughs]. It's like I took the children to see Lion King, you know, and all what was the message that came through, we're all different stages in the chain of life and sometimes we won't acknowledge it because of shame or feeling whatever, whatever, what society would say to us, whatever, but we all belong, we all belong but something there higher, something there lower. Community for me now is something different, something else, not just the community of the church, or the people that I know or used to, or friends or, those are there and they have their place but wider than myself and my immediate family, the world is bigger and wider than my space, so you can embrace people to a level that you can just raise people to a level where they need to be raised or whatever, that's important.

LS So it seems the training or being part of the project kind of opened your eyes to a wider part of the community

CN1 Absolutely, to much, much wider. And one of the most impressive things I find about X hospice, I didn't know that so many things went on here, in X, sometimes I drop in, see different groups. I had no idea and I've lived in X since '69. So, shame on me in one sense, but that's where I was but now it's a different, so it's almost like, um, I can what I get and get what I can [laughs]. If you see my point

LS Yes

CN1 Because there is so much there which I didn't know, I didn't realise. I shut off, switch off from, walking blinkered, but now the blinkers are off, now I'm able to see wider than...

LS And that's in terms of all the different services.

CN1 All the different services, what is available. 'Cos even the X Centre, it's to do with, um, community service for young people and older people, you

know, volunteering, it's an amazing thing. And before I would just pass, if I need to go to the gas board or the shop, I will look up but it made no sense to me because I wasn't involved in it, now I realise, wow! Come on, here, this is on your doorstep, this is part of the living community. It's a lively thing, it's not a dead thing. It's not dead to me anymore.

LS And what do you think that has kind of done to you as a person, this whole range of volunteering things that you're doing?

CN1 I'm brighter for it, 'cos I feel happy because I could easily be at home sitting down reading a book or just being in my own world and not getting involved and [pauses] like that, like just drift, drift, just selfish, in a context of my family, people that I love and care for and know, the others didn't matter. It's like in this circle, but nobody can be in, see that circle [draws circle with hand] but then that circle gradually opening out in a wider...

LS Before you would have just been...

CN1 Just, yes, that little unit and this one fit in and that one fit in but now its anything goes, yeah, its like that now.

LS And you feel brighter?

CN1 Oh god, smiley, happy, just, I feel good within myself. It's a feel good factor. It's not a boasting thing, just health-wise and I can get up and feel, god, whatever I think I have, there's worse out there, no matter how bad or if feel, I don't feel any way that I need to feel when there's nothing there or looking for something that's not there. Just get on with it. It's like that, get on with it. If you've got a bad leg, then somebody has no leg, just move it, if you need treatment, it's like that. Not self-focused, just think of others out there. You know because sometimes you read and see the news but it's distant, its miles but this is here, its localised, on different levels on different grounds

LS Do you mean the kind of suffering is everywhere?

CN1 Yes, everywhere, look in your own back door, look in your neighbourhood, look in the people who live in the building that you live in. So it opens me out to a way of thinking, seeing, hearing, believing, shows me what is there. This I'm hearing, feeling, touching, smelling, tasting. So it's like my external feeds me and so my internal begins to process and see and

wonder and so I could say to somebody, 'do you know of X hospice, need support or of that community centre or that one over there'. It's like that, yeah, it widens me.

LS Big changes

CN1 Absolutely! I wouldn't want to come in here and be scornful and feel 'I don't want to see that...' It might not be said. Do you know, I have someone I walk around with [laughs] clean hands and wipes and sort of, no need. You're on the bus, that happens, just live.

LS So you don't do that anymore?

CN1 No, no, no, I have it if I need but it's not a 'you have to'. People are people, if you're going to get sick, you'll get sick. Don't put yourself in the danger but just live. It's like that.

LS Do you think that kind of means you've become a bit more trusting or open to living as part of the community?

CN1 I think I've become a bit more living among the community, a bit more open, open to change for myself and see change in people, it's like that. And change is a ... you know, you either take it or leave it and, but I process things and one day, if I was in that position, it puts me in a good place to know that if I need support there's support, all I have to do is ask for it or seek it out and I know that god forbid and the time comes to, at the point of dying or whatever, I would ask for X hospice it's not something that would 'mmmmm', I would. So it opens me out to just live and let others live and that for me is important.

LS So do you think's made you think a bit more about that time in everyone's lives they might be near the end of their life

CN1 Yes, yes

LS Consider what you'd want

CN1 Yes, though I haven't written anything about that yet [laughs]. I'm still processing, but it's not hard for me to say but before it would be like a bullet in my chest that if you operate it would kill you and if you don't... so I live with it as long as but now, you see my point, that can be shifted and I can embrace it in a way that I wouldn't before. It would just, just like what that

person said before, it would be like a whisper, now I'm able to give voice to it, so the voice could be heard, I wouldn't whisper it, I would say, 'oh yeah, X hospice and if someone on the bus and they 'oh, X hospice, quite a few times, no, no, no, no, what you're thinking, that's what someone fed you but believe you me, go there and see for yourself. So I'm able to say it in that way. Whereas before when they were speaking about X hospice, I probably give my bit about it, 'oh yes I heard about it'.

LS So what do you think that projects like Compassionate Neighbours do for a community, more broadly than just you and your person you're matched up with?

CN1 I don't know if you advertise it or if you're allowed to. Sometimes you see on the buses adverts of all different kinds and nature and I think that the amount of people that will be trained is insufficient for people to understand or grasp, what goes on or what X hospice is. So I think as well the hospitals itself is going to refer people to here so it should have some wider advert with a board or whatever, something to say X hospice is whatever, with X hospice's agreement to say, so that, it's not enough for the voice or the visit or whatever, but it needs to be on a wider, on some networks, on some television programmes, something that is visible, be heard, can be seen, because two and three is ok for here and [inaudible] on a bigger scale, advert on a bus, on a billboard, something around that, the thought of X hospice what you imagine X hospice, hey presto, it is not so. That's where, what my thinking is, we're a little drop in the ocean, as it were, ripple effect, but you need a bigger impact, wider impact, yeah.

LS We've just got a few people trained so far, but you feel the need for people to have Compassionate Neighbours is bigger than we can meet at this stage?

CN1 Bigger at the moment, yes. And it's getting worse because people are living longer, suffering in different ways, in isolation, people are losing partners and despairing, people are going through things that beyond...

LS So you think that the role of the Compassionate Neighbour is something that people need?

CN1 Yes, absolutely, on a bigger scale. I know they are gonna be doing training in other boroughs but I think these things need to be borough wide to advertise the hospice, and this is the only one in X as per say, because it's the only one in X, it needs to be bigger, big it up, in a way. And when I was coming in, I noticed the advert for the jumble sale, so maybe, something out there on a billboard, to say 'dah dah dah dah' and down the line and now people have cameras, they can internet, you know in that context. But I think billboards, it costs money but somewhere, somehow.

LS And is that sharing the message of the hospice more generally or about compassionate neighbours?

CN1 Compassionate neighbours along with the hospice, the whole package. Because if you split it up... It's important to know, because I have to say 'I'm from X hospice and that's important as a Compassionate Neighbour. So my voice at the moment is for one person and from that one person, if I see or hear people on the bus saying things, I will, but its small, drop in the ocean to really expand, you know it's like that so it needs to be on a wider level, maybe sometimes you could ask in shops and you can put leaflets in shops or something needs to be going, something that people can hold or have paper in their hand, to say, you know, because it's easy, not everybody is going to come in here to see in here, so maybe somewhere out there, in the communities, where the X, the X Community, somethings you can pick up, where people go. Shops, the most things that you see around is eating places, so, some of those things. That's my observation and see well how we make it bigger than the few that knows and hears and sees. Its insufficient to ... maybe get the parliament, the prime minister [laughs and claps]. I think I've gone off track...!

LS Not at all, I'm going to see if I have got any more... I think we've actually covered most of them.

CN1 You can pick in what I've said. But it really broadens me in a way and I see where the hospice needs to be broadened with Compassionate Neighbours. Yeah, yeah.

LS Any final reflections to share? You've shared a lot.

CN1 [laughs] I didn't know what I was in for what I was going to answer, its unprepared speech. I'm just going as go along.

LS It's exactly what we want, your thoughts about what it's meant to you and the person you're matched up with

CN1 I understand that at the beginning, this was the first one, we were the babies as it were, but the time of training to the time of matching is too long, so perhaps as the training is going along, people need to learn to know very early on that we need to have DBS and particulars upfront so the process doesn't take so long because, the training had finished, it was almost as if that didn't matter, but now X has got things off the ground and the ball is rolling, I think she's probably had more people than people are available to fit in so need to plug that gap, before it loses what it's meant to be, and the length. And I understand the mechanism of that because that particular person that was in that role was not engaging...

LS No

CN1 and couldn't apply herself to one another and I think at the point at where she needed help she could not ask for it because set yourself in that too distanced from people and pride wouldn't allow you to say, look I'm not getting it right and I can't... so therefore you fail yourself as well as the hospice. The hospice set you up to fail in one sense, if when we're having the training and you're not there, you're just flitting in and out like a butterfly, then there's no substance to the person so if you've got no substance, you can't draw from what is not there. So, then X came in, totally opposite with her animated character and in the matter of 'do, do,do' so it showed, so the learning in there is, you know, I have to see. I think it will go on, it will go on from strength to strength. It was good in one sense for that to happen, so that the learning falls down, let's work it early. Let it be known. People might be having a scare factor, we're having DBS because you don't know. So people might have all sorts of problem, all sorts that will interfere so they will back out without necessarily saying, so I think upfront, if that is said because in any situation there is a drop-out rate, so who is going to drop out, let it be early enough so you're not having false hope, you know. So of the scale of

things, it's alright, it happened for the right time and the right reason and what happened was the learning in that and if we can't learn from something then what's the point.

That is it [laughs]

LS Well thank you very much, I'm going to press stop

CN1 Take out the jumble of things I said there

LS Not at all.

Appendix 5: Coding tree excerpt

Coding Tree exported from Dedoose on 30/12/16

1. People not patients and professionals

a. Communities know this already – understanding existing community competence

- i. Different motivations, same underlying principles of wanting to do this, this should happen
 - 1. Access this common language, e.g. compassion not dying (generic wish, beyond death and dying/hospices?)
- ii. It is happening already in some places – skills and competence exists already
- iii. Capacity/competence not romanticized but all are given the opportunity to participate
- iv. People are scared – fear surrounds this
- v. One-ness or understanding of commonality

b. Acknowledge diversity of need and experience (of caring, ageing, loneliness)

- i. Experiences of illness, ageing, caring, death, loneliness are not uniform
- ii. Uniform solutions do not exist and these are not necessarily problems, just part of life (not pathologising?)
 - 1. Must be individually worked out, not an 8 week course with outcomes
- iii. For some this is an intrusion
 - 1. 'Failure'?

c. Community development focus rather than clinical

- i. Community development skills needed
- ii. Shift in focus can be difficult
- iii. Different perspective on risk
- iv. Volunteers stay as people, not professionalized

d. Creating a movement not a service

- i. Coffee mornings and ongoing social opps
- ii. Training creates smaller groups, then part of wider one

2. Developing relationships not fixing problems

a. CN compassionate community created

- i. Training focuses on building a network/relationships

1. Modelling relationship – role plays and more subtly
2. Training supports CN selection, successful matching which supports initial inclusive policy
3. Focus is on learning about self and others, not about new skills (although they are taught)
- ii. Self growth and reflection
- iii. New skills taught
- iv. Accepting, tolerant of diversity
- v. Tackles issues of loss
- vi. End in its own right for some – CNs build this around themselves

b. CNs develop reciprocal relationship with the hospice

- i. Hospice gives legitimacy and authority to CNs and trusts them
 1. Allows CNs to act with confidence and autonomy in community
 2. CNs feel they are a valued part of the hospice
- ii. CNs spread message of hospice (what?) into communities, become ambassadors

c. CNs and CMs develop reciprocal/individualized relationship

- i. Reciprocal/mutual – both expressing care or contributing to relationship/each other in different ways
- ii. Intrusion for some
- iii. Does not always work – personality dependent
- iv. Sense of being equals/peers
- v. Enjoyment, laughter, looking forward to visits
- vi. Development of intimacy
 1. Being respectful
 2. Joking
 3. Trust
 4. Love
 5. Becoming close friends/significant relationship
- vii. Long term/sustainable/cross settings
- viii. Worry for CNs and CMs – other side of caring/intimacy
- ix. Management of bereavement
- x. Not always through project – independent matches

d. CNs and CMs gain membership of a wider movement/group

- i. CN network
- ii. Hospice/volunteering
- iii. CN movement nationally/internationally
- iv. Local community – belonging?

3. Impacts

a. For people involved

- i. Feeling happier
- ii. Connected
- iii. Confident/personal change/self esteem
- iv. Sense of purpose/meaning
- v. Preparedness for own/others death
- vi. Able to undertake activities – external, physical changes to environment/activities
- vii. Dealing with own issues – mental health, loneliness, bereavements
- viii. Intrusion

b. For the hospice

- i. Changed volunteer profile
- ii. Changed attitude in communities to hospice
- iii. Challenges for staff
- iv. Conflict between external and internal perception of project
 - 1. Seen as a service
 - 2. CNs not respected and valued in reality
 - 3. Is this core work or peripheral
- v. Recognition as a leader
 - 1. Locally
 - 2. Nationally
 - 3. Internationally

c. For the wider community

- i. Lay
 - 1. Acknowledgement of capacity by an organization/legitimation of community caring
 - 2. Existing caring networks in community supported by CNs indirectly
 - 3. Compassion enacted to strangers in community
 - 4. Changes in CNs approach to friends and family
 - 5. Changed approach of CNs in employment
 - a. Carers
 - 6. Independent matches taking place
- ii. Professional
 - 1. Professional dominance of care challenged
 - a. Practical, witnessed examples of how this can work (GPs witnessing this care)
 - 2. Hospice/death and dying seen as part of solution to ageing etc – part of wider healthcare economy
- iii. Social ecological changes hinted at

Appendix 6: Consolidated criteria for reporting qualitative studies (COREQ)

(Tong, Sainsbury and Craig, 2007)

No. Item	Guide questions/description	Reported in chapter
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	5
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	2
3. Occupation	What was their occupation at the time of the study?	5
4. Gender	Was the researcher male or female?	10
5. Experience and training	What experience or training did the researcher have?	4
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	2
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	2,4,10
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	5
12. Sample size	How many participants were in the study?	5

13. Non-participation	How many people refused to participate or dropped out? Reasons?	5
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	5
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	5
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	5
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	5
20. Field notes	Were field notes made during and/or after the inter view or focus group?	5
21. Duration	What was the duration of the inter views or focus group?	5
22. Data saturation	Was data saturation discussed?	4,5
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	5
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	5,10
25. Description of the coding tree	Did authors provide a description of the coding tree?	Appendix 3
26. Derivation of themes	Were themes identified in advance or derived from the data?	4, 5
27. Software	What software, if applicable, was used to manage the data?	5
28. Participant checking	Did participants provide feedback on the findings?	5
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6, 7
30. Data and findings consistent	Was there consistency between the data presented and the findings?	6,7,8

31. Clarity of major themes	Were major themes clearly presented in the findings?	6,7,8
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	9

Appendix 7: Publications during the doctoral study period

[with CRediT taxonomy of author contributions (Brand, Allen, Altman, *et al.*, 2015)]

Paper One:

Paul, S. & Sallnow, L., 2013. Public health approaches to end-of-life care in the UK: an online survey of palliative care services. *BMJ Supportive & Palliative Care*, 3, pp.196–199. [Permission to reproduce applied for]

CRediT: *P.S. and L.S. conceived the study jointly, P.S. drafted the first survey tool, L.S. and P.S. revised the survey tool, designed the methodology, collected the data, analysed the data and wrote and edited the paper jointly.*

Paper Two:

Sallnow, L. & Paul, S., 2015. Understanding community engagement in end-of-life care: developing conceptual clarity. *Critical Public Health*, 25(2), pp.231–238.

[Permission to reproduce applied for]

CRediT: *L.S. and P.S. conceived the study jointly, designed the methodology, created the figure and wrote and edited the paper jointly.*

Paper Three:

Sallnow, L., Richardson, H., *et al.*, 2016. The impact of a new public health approach to end-of-life care: A systematic review. *Palliative Medicine*, 30(3), pp.200–211. [Permission reproduce granted]

CRediT: *L.S. conceived the study independently, designed the methodology, collected and analysed the data independently. H.R. assisted with analysis of a subsection of data for validity. L.S. wrote the original draft of the paper. S.M. and A.K. supervised the study and H.R., A.K., S.M. commented on the final version.*

Paper Four:

Sallnow, L., Tishelman, C., *et al.*, 2016. Research in public health and end-of-life care – Building on the past and developing the new. *Progress in Palliative Care*, 24(1), pp.25–30. [Permission to reproduce applied for]

CRediT: *L.S., C.T., O.L., H.R., J.C. jointly conceived the paper and contributed to content for the first draft. L.S. wrote the first draft with supervision support from J.C.*

Public health approaches to end-of-life care in the UK: an online survey of palliative care services

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ABSTRACT

Aims and objectives The public health approach to end-of-life care has gained recognition over the past decade regarding its contribution to palliative care services. Terms, such as health-promoting palliative care, and compassionate communities, have entered the discourse of palliative care and practice; examples exist in the UK and globally. This scoping study aimed to determine if such initiatives were priorities for hospices in the UK and, if so, provide baseline data on the types of initiatives undertaken.

Methods An online survey was designed, piloted and emailed to 220 palliative care providers across the four UK countries. It included a total of six questions. Quantitative data were analysed using descriptive statistics. Qualitative data were analysed thematically.

Findings There was a 66% response rate. Of those providers, 60% indicated that public health approaches to death, dying and loss were a current priority for their organisation. Respondents identified a range of work being undertaken currently in this area. The most successful were felt to be working with schools and working directly with local community groups. The findings demonstrate the relevance of a public health approach for palliative care services and how they are currently engaging with the communities they serve. Although the approach was endorsed by the majority of respondents, various challenges were highlighted. These related to the need to balance this against service provision, and the need for more training and resources to support these initiatives, at both national and community levels.

INTRODUCTION

A public health approach to palliative care has gained policy, practice and literature focus, both in the UK and globally. Public health is a broad term focused on

improving the health of populations, but the changing health landscape has necessitated new ways of working, beyond traditional public health measures. The importance of engaging communities in their own care has been recognised, and this now occupies a central place in many fields in health.^{1 2} Community engagement exists on a spectrum that extends from informing at one end to empowerment at the other, distinguished by the extent to which power is shared with the community.³ These principles have resonated for many within palliative care, and examples exist worldwide.⁴⁻⁷ At one end of the spectrum, approaches that work to promote public openness around death, dying and loss can tackle the stigma that can surround these issues. Approaches that focus on empowering people, families and communities allow them to draw on their own resources and community supports to adapt and cope. A range of terms exists to describe these approaches, including a public health approach, health-promoting palliative care and compassionate communities. In the UK, end-of-life care policy documents have recognised the significance of such approaches,^{8 9} but little research exists in this field. This study aimed to determine whether such public health approaches were a priority for UK palliative care services, and to obtain a baseline of current initiatives.

METHODS

An online survey was developed based on current gaps within the literature, highlighted by the authors' doctoral literature reviews. It consisted of six questions and was piloted before use. Quantitative data included questions on organisational remit and demographics, as well as asking participants to indicate, from a range of

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responses, the extent that this type of work is a priority, and if any projects were undertaken in this area. Qualitative data was requested by inviting participants to highlight which areas of work they felt were successful and why, as well as providing comments on the role of palliative care services in relation to public health approaches to end-of-life care. Ethical approval was not required as per NHS ethical review guidelines. The University of Edinburgh ethical review process was undertaken, however, confirming the survey as Level 1: 'no special ethical risk'.

A total of 220 services were contacted, identified via the Help the Hospices Directory.¹⁰ This included both independent hospices and palliative care inpatient services, usually attached to hospitals. Five organisations were located in Northern Ireland, 19 in Scotland, 14 in Wales and 182 in England. A link to the survey was emailed directly to the Chief Executive or the generic email if this was unavailable, with a brief overview of the purpose of the study. All responses were anonymous. Quantitative data were collated and analysed using descriptive statistics. Qualitative data were analysed thematically. This was done individually by the investigators in the first instance, with identified themes being brought together and discussed to achieve consensus.

FINDINGS

Of the 220 services contacted, 146 (66%) returns were received over 3 weeks from all four countries in the UK. Sixty per cent of respondents identified public health approaches to end-of-life care as a priority for their service. A further 30.8% noted that such approaches were not currently a priority but could be in the future. Only 7.6% of respondents felt that such practice was not a priority for their service. This was due to a lack of resources, or because it was felt that a public health approach did not fit with the remit of the service. Priority did not appear to be determined by whether or not the service covered a rural, urban or mixed area, or by the range of services provided.

Working with schools was the most common project undertaken by services identified by 73.3% of respondents. This was followed closely by engaging with local media (69.2%). Other examples included: providing public education and awareness events (61.0%); attending community events (59.6%); supporting community dialogue about end-of-life care issues (46.6%); working with faith groups around loss, death, dying and hospice care (44.5%); and engaging with local business on issues related to loss, death, dying and hospice care (32.2%). Respondents were also invited to include additional projects that had not been identified as a specific response option. These included: awareness raising of the hospice and/or cancer; promoting 'Dying Matters' week; developing compassionate communities; and fundraising. Fundraising was described in its ability to both raise

the profile of hospice within the community but also give 'people an opportunity to come and talk about death and dying'.

Table 1 identifies which projects respondents felt were most successful. Responses fell across five themes encompassing a range of practices. A number of respondents commented that 'one approach doesn't work' and a diversity of approaches was more likely to be successful.

Participants were also asked to comment on the role palliative care services could play in public health approaches to end-of-life care. The majority of responses described the pivotal role that services have due to their expertise in end-of-life care, existing positive relationships with local communities, and opportunities that exist within current service delivery. It was also highlighted that such practice could potentially benefit service delivery by influencing equitable care and challenging stigma related to hospice care. A number of challenges in taking forward such approaches were also acknowledged. These included: a lack of resources; the potential impact on direct service delivery; cultural issues; recent changes to care services; stigma associated with hospice care; and a lack of staff skill, training and resources. It was suggested that a national approach would be required to take this further. Two comments included reservations about a public health approach to death and dying in general, which was deemed to be unachievable or 'reaching for a rainbow'.

DISCUSSION

This is the first study to demonstrate that public health approaches to end-of-life care are a priority for the majority of palliative care services in the UK. Although this overview illustrates both the range of the approaches used and communities engaged, it also demonstrates that there is a lack of clarity surrounding what constitutes a community engagement initiative per se, and what may be part of fundraising or core service, a finding that has been noted elsewhere.¹¹ For example, responses describing the introduction of the Liverpool Care Pathway into nursing homes illustrate that confusion exists between community engagement initiatives and the community as a site for service delivery. This survey records the important opportunity that events, such as Dying Matters week, offer to meet with local communities, a first step in engagement.

Despite limited published literature in the UK, the results of this study correlate with emerging international literature. The theoretical basis for the public health approach was developed in Australia by Kellehear.^{12 13} Examples published from India,⁴ Australia^{5 7 14 15} and the UK,⁶ describe the role community engagement has played in both increasing access to services and improving the holistic nature of care.

This study has three limitations. Designed as a scoping survey, the tool was only piloted and did not

Short report

Table 1 Projects discussed by respondents as successful

Project	Description	Examples
Work with schools	<ul style="list-style-type: none"> ▶ Providing bereavement support with individuals and staff ▶ Engaging pupils in conversations on palliative care, death, dying and bereavement 	<p>"Meeting with schools through interested groups e.g. health and social classes"</p> <p>"Work on bringing together school children and hospice patients. Exceptionally positive feedback from all stakeholders, including patients, and greater anticipated benefits from the patients involved"</p> <p>"Our bereavement service work with local schools—this is very good work and means that staff working with schools are able to deal with death and bereavement when it occurs"</p> <p>"Mainly working with schools where a loss of a parent or grandparent has provoked a reaction"</p>
Engaging with community groups and organisations	<ul style="list-style-type: none"> ▶ Providing education and information ▶ Sharing expertise ▶ Raising the service profile ▶ Fundraising <p>Examples of groups included: businesses, faith groups, nursing homes, professionals and other charities</p>	<p>"Engaging with local business to promote hospice care and, in particular, to supporting people to die at home with enhanced specialised nursing support. The media attention relating to this has been of mutual benefit for all parties with continuing supportive relationship developing as part of social responsibility"</p> <p>"Multi-faith session regarding end of life care, cultural beliefs and rituals and where the hospice can fit in" "introduction of LCP [Liverpool Care Pathway] to nursing homes"</p> <p>"We have a community development approach to working with our South Asian community"</p>
Awareness raising	<p>Projects to raise awareness of:</p> <ul style="list-style-type: none"> ▶ The hospice ▶ Health issues, such as cancer ▶ End-of-life care issues 	<p>"Community events have been quite successful as people do not expect us to have a stall which we mainly use for dying matters material rather than leaflets about the hospice"</p> <p>"Participating in 'Doors Open Days'"</p> <p>"Radio—a good communication channel"</p> <p>"We have a resource and information centre in a prime town centre"</p> <p>"We have a community social programme; this means that the general public can access our restaurant, information and social areas at all times"</p>
Compassionate communities	Using compassionate community frameworks to develop community support networks	<p>"The hospice adopted 'The Reaching People Agenda' which means promoting compassionate communities work"</p> <p>Compassionate communities "has been locally audited for the impact of use of local health services which has revealed downward trend on most measures"</p>
Dying matters	Using 'Dying Matters' as a focus to raising awareness and engaging the community	<p>"Dying matters events bring the subject to the fore"</p> <p>"Dying matters has enabled us to reach a number of communities, networking with our community colleagues from health, social care and local schools"</p>

undergo reliability and validity testing, meaning more in-depth conclusions are not possible. The sample of service providers was taken from the 2009/2010 Help the Hospices Directory, meaning some inpatient units were included who may not have the remit to initiate such services, and that the list of services may be out of date. Owing to the anonymous nature of the survey, the demographics of non-responders are not available to determine their characteristics and significant differences.

This study has five important implications. The challenges highlighted demonstrate the need for innovative practice and skills to be shared between services, and for national guidance or toolkits to support services interested in this work. National campaigns, such as Dying Matters, have provided resources and opportunities to hold events, and further work like this should be supported. Engaging with communities requires local knowledge, however, and involves more than simple awareness raising. Genuine engagement with communities requires open and honest dialogue and working together in partnership. It is this

collaborative process that can deliver real improvements in equitable access, services and society's attitude to death and dying.

This is an under-researched area, and conceptual clarity of what the approach comprises and does not, is essential. A series of case studies and detailed evaluations of these initiatives from various perspectives are needed to underpin future work.

CONCLUSION

Community engagement in palliative care is a priority for services in the UK, and a diverse range of initiatives are taking place currently. For this field to develop further, research and guidance is needed to support services to work in partnership with the communities.

I believe that [this approach] presents an opportunity for hospices to re-engage with voluntary community-based support and therefore represents a return to its 'roots' i.e. citizens developing their own capacity to care [Quotation from respondent]

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Contributors The idea for this scoping study developed due to a lack of literature in this area, identified by both Sally Paul and Libby Sallnow as part of their PhD studies. A survey, originally designed by Sally Paul as part of her initial PhD research design, was therefore adapted and developed by both authors to be used for the purpose of the study. Both Sally Paul and Libby Sallnow played an equal role in conducting the research, processing the findings and writing this short report. Due to this, both authors are responsible for the overall content of the report and can act as guarantors.

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Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.

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COMMENTARY

Understanding community engagement in end-of-life care: developing conceptual clarity

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Over the past decade, public health approaches to end-of-life care have received increased literature, policy and practice focus. These developments recognise the significance of community engagement activities and their contribution to end-of-life care. In the United Kingdom, community engagement is a priority for the majority of hospices. Nevertheless, there exists some ambiguity about the range of different practice that exists under this heading, the principles underpinning it and the outcomes for the work. Conceptual clarity is an essential next step in the development of this emergent field. The aim of this paper is to present a definition and a conceptual model of community engagement for end-of-life care services and the communities they serve. A spectrum of community engagement in end of life care is presented, derived from models in the general community engagement literature. Types of engagement extend on a continuum from *informing* through *consulting*, *co-producing*, *collaborating* to *empowerment*, with the later levels capable of achieving more penetrating health and social change. The factors that affect the type and nature of engagement are represented in boxes at either end, demonstrating that it is not the influence of a single factor, but the overall balance of factors that determines the quality and outcomes of the engagement work. This spectrum is designed to aid professional services and the communities they serve to embark on community engagement projects with an open awareness of the requirements and key components underpinning their success and a shared understanding and language.

Keywords: community; death; health promotion

Introduction

Community engagement and related terms are being used with increased frequency in health and social care policy and practice both in the UK (Department for Communities and Local Government, 2006; Department of Health, 2004; NICE, 2008) and internationally (Commission on Social Determinants of Health, 2008). These concepts have influenced thinking on research governance and ethics, with community engagement being seen as an increasingly important requirement of research, particularly with marginalised or disadvantaged communities (INVOLVE, 2012; Tindana et al., 2007). The reasons for engaging communities in their own care are clear: services designed and implemented in partnership with communities are more likely to meet the needs of

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those communities and to be accessed by larger numbers of users; those with ongoing community involvement are more likely to be responsive to changing need and to be sustainable; and the skills developed within a community when working on such projects can have a wider impact, including building community capacity, changing health behaviours, tackling the social determinants of health, improving well-being and developing social capital (Hawe & Shiell, 2000; NICE, 2008; O'Mara-Eves et al., 2013; Popay, 2010).

Community engagement may be firmly embedded in mainstream health care rhetoric but the term can denote a variety of practices (Attree et al., 2011; Popay, 2010). Morgan (2001) has described the tensions that can exist with the use of the term community participation being used either for its cosmetic value or, simultaneously, by different actors to advance conflicting goals. Aside from terminological tensions, there can be a gulf of understanding between practitioners. Some see participation as a means to achieving changes in health status or other outcomes, whereas others see it as an end in itself, where increased participation and empowerment are the goals of the process. Morgan (2001) has provided a definitional divide for this. She describes community participation as *utilitarian* when it involves the use of community resources to achieve an end, and as an *empowerment* model when it aims to give communities the responsibility to change conditions.

Community engagement in end-of-life care

The relevance and potential of engaging communities has been recognised in the end-of-life care literature for over a decade (Kellehear, 1999), and increasingly in UK (Department of Health, 2008; Scottish Government, 2008) and international (Paleri, 2008) policy. Palliative care already shares many of the principles fundamental to the new public health approach. These include a belief in a holistic or ecological view of health, a focus on individual and community specific needs, and recognition of the limitations of traditional models of health care delivery. Examples of end-of-life care services engaging with communities exist worldwide and a range of terms have now entered the discourse, including 'public health approaches to palliative care' (Conway, 2008), 'compassionate cities' (Kellehear, 2005), 'compassionate communities' (Abel, Bowra, Walter, & Howarth, 2011) and 'health promoting palliative care' (Kellehear, 1999). Such initiatives serve to: improve the relevance of the services offered; develop skills, knowledge and capacity in communities; support coping and resilience in the face of death, dying and loss and minimise associated harm; and support healthier societal attitudes to these issues.

End-of-life care has faced a number of challenges in recent years. Inequity of access has been highlighted (Sims, Radford, Doran, & Page, 1997), as has the often limited interpretation of holistic care, focusing on physical or psychological symptom burden at the expense of social or spiritual needs (Kearney, 1992). The field has also been criticised for becoming increasingly professionally led and fostering dependence on professionals, rather than on individual coping (Randall & Downie, 2006, p. 149). This is seen as particularly perilous, given we live in a society where people are living longer and the number of deaths per year for older people is expected to rise (Cohen & Deliens, 2012). Although a recent analysis concluded that predicted figures for old age dependency are less alarming when additional demographic changes, such as altered working patterns and increasing life expectancy are considered (Spijker & MacInnes, 2013), estimates of the need for palliative and long-term supportive care continue to

increase (Murtagh et al., 2014). Development of sustainable community support structures through community engagement is one way in which the problems of continuity of care and equity can be addressed. It allows for the provision of a continuous background level of support that is developed pertinent to specific needs within the community, upon which discrete episodes of professional intervention can occur, both during illness and into bereavement.

A recent survey documented the substantial interest in these approaches within the UK hospice sector, with over 90% of respondents indicating that community engagement initiatives were either a current or future priority (Paul & Sallnow, 2013). A 2013 report which comprised a series of 28 case studies detailing work carried out by end-of-life services in England under the banner of 'compassionate communities' further demonstrated the interest and commitment that exists within the field (Barry & Patel, 2013).

However, the semantic confusion with the term community engagement in the general literature also exists within end-of-life care, where it is used to refer to both engagement work with a community and the community as a site for service delivery (Paul & Sallnow, 2013). The deep roots many hospices have in their local communities mean that fundraising and support from a long-serving cohort of volunteers is an integral part of their work with the local community. Much of this work may differ qualitatively from work designed to empower the local community more broadly in issues relating to death and dying. In order to describe, share and develop best practice in this area, the field requires a shared understanding and language. Thus, the aim of this paper is to present a definition and conceptual model through which the principles underlying community engagement in end-of-life care may be understood.

A definition of community engagement in end-of-life care

Our proposed definition draws on a range of existing definitions for community engagement and participation (Arnstein, 1969; Fawcett et al., 1995; O'Mara-Eves et al., 2013; Popay, 2010).

Community engagement in end-of-life care is an umbrella term for a process which enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement and their related well being. It exists on a spectrum of engagement that extends from informing through to empowering, depending on a range of factors such as the degree of participation from the local community and the intention of the work. Community engagement activities by end-of-life care services go beyond working in the community to working with the community to improve its experience of end-of-life care.

Conceptual clarity: community engagement and the role of a spectrum

The range of work that can fall under the term community engagement has prompted authors in diverse fields to develop conceptual diagrams, ladders or schemata to describe and catalogue the scope of practice. Many of these have taken the form of hierarchical diagrams of ladders or steps, demonstrating increased participation and power sharing at each rung (Arnstein, 1969). Although useful in demonstrating the impacts of sequential ceding of power by authorities, one-dimensional models have been criticised for their simplistic description of the process, in not recognising, for example, the dynamic structures that are required in engagement (Tritter & McCallum,

2006) or that communities also have agency and power that can be shared (Tritter, 2009). Alternative models have subsequently been proposed. For example, Tritter and McCallum (2006) adopt the analogy of a mosaic to represent the number of interlinkages that are required for meaningful involvement, in an attempt to capture the nuances and complexities that exist within patient and public involvement in the NHS. Gibson, Britten and Lynch (2012) offer a four-dimensional model, again for patient and public involvement, to allow for the inclusion of the pluralism of values, ideologies and social groups that can be involved. Popay (2010) incorporated a hierarchical model with a range of outcomes extending from service through to health and social outcomes and demonstrating how the more penetrating health and social outcomes are only achievable through higher levels of participation.

A spectrum of engagement in end-of-life care

A spectrum of community engagement in end-of-life care is presented in Figure 1. It is based on existing models within the generic literature (Amstein, 1969; Oliver et al., 2007; Popay, 2010; Tritter & McCallum, 2006) and has been adapted iteratively following comments and revisions. We acknowledge the extensive literature regarding the definition of community. The decision not to define the term for this paper is intentional, leaving communities and services free to interpret the term as they see fit and to adapt it to the local context.

Although acknowledging the limitations of the various models that have been proposed before, this spectrum employs a hierarchical model to place emphasis on the progressive development of community capacity, quality of care, and health and wellbeing. The dynamic and diverse nature of community engagement is represented in the boxes at either end which describe the range of influencing factors and dimensions of the work. It is the overall balance of these factors that determines the quality of the work and the eventual outcomes, rather than the impact of a single factor. Five types of engagement work are represented along the length of the spectrum. Rather than discrete categories, they are located along a continuum. The types of work on the right-hand side represent more meaningful forms of engagement and those capable of more penetrating health and social outcomes. 'Inform' represents the organisation telling the community about, for example, services they offer or public health messages. Leaflets,

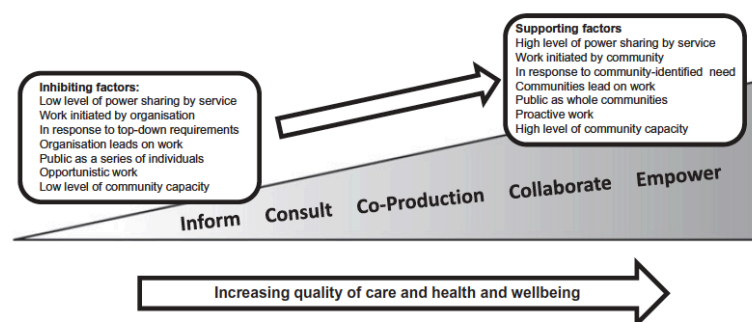


Figure 1. Spectrum of engagement in end-of-life care: developing community capacity.

websites or open days would fulfil this aim. The community is passive in this work, with the aims being to raise awareness rather than to involve them in the work. 'Consult' describes efforts by the service to gather views from the community. These views may or may not be used by the organisation to design services or understand local need, but the movement of information is one way; no feedback is given to the community. Examples would include surveys or public meetings. 'Co-production' requires organisations to determine the views and needs of the local community and then allow the community to determine how well this information has been incorporated or acted upon. User groups would support this type of work, with an ongoing relationship developing through the work. 'Collaborate' is focused on partnership working and involves participatory decision-making. Communities are supported to develop alternative models of care and to deliver these jointly with the service. An example could be of a community group taking over provision of a befriending service for socially isolated people, with the organisation retaining overall control and support of the project. Finally, 'empower' necessitates the community taking full control of an aspect of care and developing its own responses. The service provides specialist support where needed but the design and delivery of the work is done by the community. This could include a community determining the need for better support around loss and developing a series of community drop in groups run by volunteers, linking with the police, local hospitals and funeral directors. The impacts are thus experienced beyond the hospice.

There are a large number of factors that can influence community engagement work and a number are represented in the boxes in Figure 1. Although they describe polarised, opposing situations, a continuum exists between them. Two fundamental factors are the degree of power sharing by the organisation and the capacity of the community to mobilise their skills and resources. Community capacity can be conceived both as a requisite for engagement and also as an outcome. Who initiates, and subsequently leads on the work, will have an important influence on the quality of the engagement. Following on from this, knowledge of where the impetus for the engagement work originated from is important. For example, top-down directives to increase user involvement will lead to a different type of engagement work to that which came from a need determined by the community. In the same way, work that involves discussions with members of the community who are already involved as volunteers or through patient care can be described as opportunistic and is likely to lead to more limited long-term outcomes as compared with work that seeks proactively to engage members of the community who may not be aware of or accessing the service. Finally, the nature of the community or public that is being engaged with must be considered. Engagement with a series of separate individuals may evolve to work with the representatives of a number of community groups and this may then lead to direct work with larger groups of people from the local communities, resulting in more wide-ranging outcomes.

Discussion

This spectrum is designed to aid professional services and the communities they serve to embark on community engagement projects with an open awareness of the key components underpinning their success. It allows for current and past projects to be reflected upon and evaluated by situating them on the spectrum and determining where the balance of factors fell. The use of shared language is an important output. The spectrum allows the related areas of volunteering and fundraising to be understood. They are often placed under the heading of community engagement but the spectrum makes

it clear that they differ conceptually. Of course, fundraising and volunteering may form important strands to stronger engagement initiatives but it is important to understand that traditional volunteering and fundraising do not aim explicitly to develop community capacity and are therefore situated on the far left of the spectrum.

In earlier iterations, the spectrum included core service on the far left-hand side of the spectrum. This was to represent the fact that, for some, core service provision includes raising awareness in the local community, leading up to empowering people and their families in self-care and coping. These are omitted in this version, which assumes that all core service should involve elements of informing, consulting, co-production, collaborating and empowering to a greater or lesser extent, but that this work is differentiated from community engagement as it focuses on people defined as patients and their families. Community engagement work is explicitly situated within the wider community. This highlights an important point, namely the important distinction between work based *in* the community (but involving patients), vs. work *with* the community. The spectrum can be used to determine how work in the community setting, such as educational or training initiatives, differs to community engagement per se.

Conceptual models or schematic representations are inevitably limited (Byock, 1997). By definition they miss the subtleties and complexities that exist in practice. This model attempts to represent some of the nuances inherent in this work but it must be taken as a guide only. Conceptual models also represent thinking and research at a particular point in time. They must be revised and refined in order to reflect current thinking, practice and research. This model is designed for a practitioner audience and as such reflects a professional, health services perspective. The authors invite reflections and critiques as to how this model could be changed or adapted to make it more useful for and reflective of practice.

Conclusion

The spectrum presented in this paper provides a framework through which the emerging and diverse field of community engagement in end-of-life care can be understood. Armed with a shared language and an appreciation of the influences, underlying principles and possible outcomes of the work, examples throughout the UK and further afield can be examined and used to inform future practice. It is hoped this will support progress and consolidation within the field, equipping end-of-life care service providers and communities with the building blocks to take forward work in this important area.

Acknowledgements

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The impact of a new public health approach to end-of-life care: A systematic review

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Abstract

Background: Communities play an increasingly significant role in their own health and social care, and evidence demonstrates the positive impact of this work on a range of health outcomes. Interest is building regarding the application of the principles of the new public health approach to those facing the end of life and their families and communities.

Aim: To review the evidence relating to the impact of a new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

Design: A systematic review employing narrative synthesis. Both meta-ethnography and the use of descriptive statistics supported analysis.

Data sources: Eight databases (AMED, ASSIA, BiblioMap, CINAHL, Cochrane Reviews, EMBASE, MEDLINE and PsycINFO) were searched from the earliest record to March 2015 using set eligibility criteria.

Results: Eight articles were included in the analysis. Three main themes emerged from the meta-ethnography: making a practical difference, individual learning and personal growth and developing community capacity. The quantitative findings mapped to the meta-ethnography and demonstrated that engaging communities can lead to improved outcomes for carers such as decreased fatigue or isolation, increase in size of caring networks and that wider social networks can influence factors such as place of death and involvement of palliative care services.

Conclusion: Evidence exists for the impact of community engagement in end-of-life care. Impact assessment should be an integral part of future initiatives and policy makers should recognise that these approaches can influence complex issues such as carer support, community capacity, wellbeing and social isolation.

Keywords

Palliative care, public health, health promotion, community engagement, impact, outcomes

What is already known about the topic?

- Community engagement is increasingly acknowledged as contributing important outcomes for health and wellbeing.
- Community engagement in end-of-life care is increasingly recognised in policy documents and practice examples exist worldwide.
- Little evidence exists regarding the impact of such approaches.

What this paper adds?

- This review demonstrates positive outcomes resulting from community engagement in end-of-life care, for individuals with life-limiting illnesses, their carers, community members participating in care and the community as a whole.

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Implications for practice, theory or policy

- The qualitative synthesis provides a map of the range and type of impact that can be experienced. Few aspects have been measured, demonstrating the research gaps in the field currently.
- Evidence demonstrating positive impacts of engaging communities in end-of-life care is of relevance to policy makers and funders, particularly when seeking to address complex issues of carer support, community capacity, social isolation and wellbeing.

Introduction

A public health approach to palliative care has been advocated by the World Health Organization since the 1990s, with the aim of improving opiate availability, developing appropriate policies and integrating palliative care services into the mainstream.^{1,2} The World Health Assembly recently recognised palliative care as a component of universal health coverage, recommending integration from the level of civil society to hospital care.³ While these remain important concerns for many delivering palliative care services, the contemporary challenges of social isolation, the professionalisation of dying, inequity of access to services and changing demographic trends have led to new pressures, and have prompted many to return to the principles of a public health approach, re-examining it in the light of these present-day challenges.

Public health encompasses a broad range of approaches, from the traditional techniques of disease control and prevention, to the newer approaches of health promotion, focusing on education and empowerment. The emergence of a health-promoting approach in the 1980s paved the way for 'new public health', placing people as active participants in their own health and recognising the importance of the social determinants of health. The Ottawa Charter⁴ was the central document in developing the new movement. It was based on five pillars or goals which should be addressed in order for a population's health to be improved: build healthy public policy, create supportive environments, strengthen community action, develop personal skills and reorient health services. Over recent years, the evidence base for such approaches has developed. A health promotion approach has been used successfully in fields such as HIV/AIDS and cardiovascular disease for decades, with important improvements in health outcomes⁵⁻⁷ and calls are increasingly being made to incorporate community engagement into healthcare more generally.⁸⁻¹⁰ A recent meta-analysis concluded that there is solid evidence that engaging communities in health projects leads to improvements in health behaviours, health consequences and self-efficacy, across a range of diseases and conditions¹¹ and the evidence base for why such approaches are needed is building, with the effect of social isolation on survival quantified¹² and the impact of strong social networks in preventing admissions to secondary care and in substantial health service cost savings demonstrated.¹³

A health-promoting or new public health approach to end-of-life care was first outlined by Kellehear¹⁴ and now encompasses a large-scale, international effort to incorporate the principles of health promotion into end-of-life care. It can be understood as a series of social efforts by communities, governments, state institutions and social or medical care organisations that aim to improve health and wellbeing in the face of life-limiting illness.¹⁵ Although the juxtaposition of health promotion and end-of-life care has been thought to be contradictory,¹⁶ it is now widely acknowledged that health and wellbeing can be improved in the context of a life-limiting illness, both for the individual and those around them. The morbidity and mortality associated with being a family caregiver, being bereaved or becoming socially isolated are well documented,^{12,17-19} in addition to the impact of suffering with a life-limiting illness. A health-promoting approach to end-of-life care argues that the answers to the above problems do not lie in increased services and more professionals. Rather loneliness, stigma and other social problems are best tackled by friends or community members rather than healthcare professionals. A strong community response augments rather than supplants the professional response.

Examples now exist throughout the world of the application of health-promoting principles to end-of-life care. These incorporate a range of processes, determined by local need and resources and a descriptive literature is building, documenting these interventions. Projects frequently describe the mobilisation of community resources, either through naturally occurring social networks^{20,21} or externally facilitated ones,^{22,23} or through the direct support of trained community volunteers.^{24,25} Other projects describe attempts to influence society's perception of and reaction to death and dying, such as through work with schools,^{26,27} businesses²⁸ or professionals^{29,30} or offer seed grants to communities to develop work themselves.^{31,32} Others still focus on awareness, education and training of community members directly in topics such as writing a will and advance care planning^{33,34} or efforts to explore society's perception of the issues through local or national conversation.³⁵⁻³⁷ Policy examples exist where lobbying from local services and communities has led to policy reform³⁸ and the emergence of dementia-friendly communities is an example of how the environment may be manipulated to improve experiences of those living with life-limiting illnesses.³⁹

Although a range of practice exists under the heading of health-promoting end-of-life care, a dominant interpretation has been through the strengthening community action pillar of the Ottawa Charter, involving community engagement, participation or development and often described using the phrase 'compassionate communities'.^{40,41} The rise in interest in these approaches has not been matched by a rise in the evidence supporting their use. With the importance of measuring outcomes in end-of-life care recognised,⁴² a need exists to understand and measure the impact of this work. This systematic review aims to determine the impact of a health-promoting or new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

Method

Search strategy

Eight databases were searched (AMED (1985–2015), ASSIA (1987–2015), BiblioMap (2015), CINAHL (1983–2015), Cochrane Reviews (1996–2015), EMBASE (1980–2015), MEDLINE (1966–2015) and PsycINFO (1806–2015)) using a search strategy based on MEDLINE search terms and adapted for other databases as necessary (Appendix 1). The search was limited to adult participants (>18 years). Reference lists of key papers were searched, key authors' publications searched, three journals were hand-searched from the first issue to March 2015 (*Journal of Palliative Care*, *Palliative Medicine* and *BMJ Supportive and Palliative Care*), experts within the field were contacted and a specialist librarian supported the search strategy.

Eligibility

Papers were included if they reported on the outcomes of community engagement, mobilisation or social network development in end-of-life care. All potential stakeholders were included as participants. Both naturally occurring examples and those resulting from an external intervention were included. Only original, published studies were included and no papers in languages other than English were identified.

Screening and data extraction

Searches were performed by one author (L.S.) against the eligibility criteria and excluded articles discussed with a second author (H.R.). Figure 1 represents the selection process. The full text papers ($n=8$) were reviewed by one reviewer first (L.S.) and a second reviewer (H.R.) independently reviewed four randomly selected papers. Disagreements were resolved through discussion with the two remaining authors (S.M. and A.K.). Data were extracted into a data extraction table (Table 1).

Quality assessment

All studies were assessed for methodological quality. The heterogeneity of the papers required a broad approach to quality and the checklist proposed by Hawker et al.⁴⁷ allows research from different paradigms to be graded. The score ranges from 1 (poor) to 40 (good). One reviewer (L.S.) graded all the studies and this was verified by a second reviewer (H.R.). Two authors of papers included in the final analysis were contacted for clarification.

Analysis

The papers retrieved were heterogeneous in study design, meaning a technique for synthesising diverse sets of data was needed. The technique of narrative synthesis⁴⁸ was utilised as it offers a robust means of analysing and synthesising quantitative and qualitative data. It aims at producing a synthesis that is useful for and targeted at practitioners in the field. The qualitative findings were combined using the technique of meta-ethnography, and the quantitative findings using descriptive statistics. The systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).⁴⁹

The process of meta-ethnography according to Noblit and Hare⁴⁶ was followed. First-order (verbatim quotes from study participants or descriptions from the authors) and second-order constructs (interpretations made by the authors) were extracted. These key concepts were then translated into one another, starting with a comprehensive paper first²³ and matching these with concepts from subsequent papers, in chronological order. Concepts were assessed for congruence, refutation or whether a new concept was being presented. These concepts were then put through a process of reinterpretation, using thematic analysis, to determine higher order themes that made sense of the studies as a whole and offered new insights to the collective data.

Results

Eight papers were included in the final analysis: three qualitative papers,^{23,25,43} three mixed methods papers^{20,33,45} and two quantitative papers.^{44,50} Papers came from a range of countries and settings (see Table 1). Four studies concerned two datasets, analysing different components of the data: Jack et al.²⁵/Jack et al.⁴³ and Horsfall et al.²³/Leonard et al.²⁰ Two studies examined the impact of naturally occurring social networks,^{30,45} two studied a mix of naturally occurring and facilitated networks,^{20,23} one examined a facilitated network approach,⁴⁴ two examined trained community volunteer support^{25,43} and one a community education project.³³

Study quality varied from good to moderate quality, with scores ranging from 27 to 37. The three qualitative

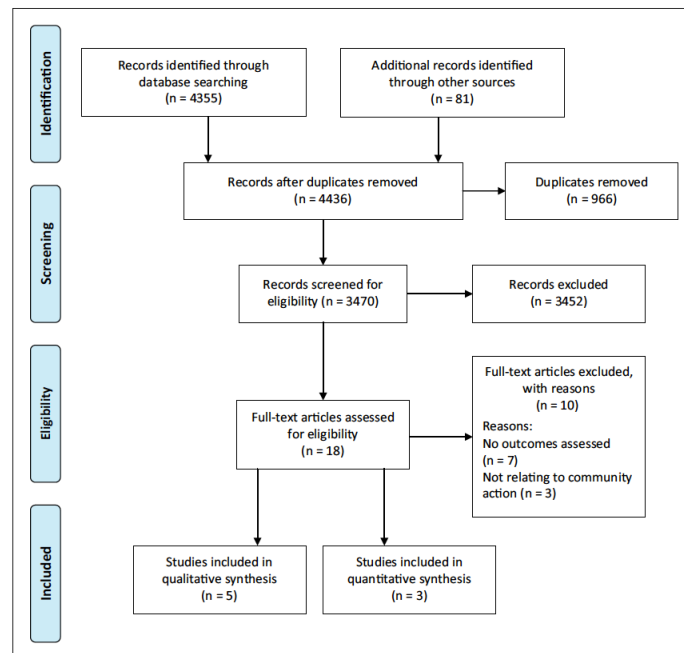


Figure 1. PRISMA flow diagram.

papers^{23,25,43} scored similarly well, with the analysis process described and extensive use of verbatim quotes. The two papers by Jack et al.^{25,43} include interpretations of a more descriptive nature, whereas the paper by Horsfall et al.²³ presents higher levels of abstraction in their interpretations. No discussion of reflexivity was undertaken in any of the papers. The two quantitative papers were both judged to be of a high quality and both included rigorous analysis of relatively large populations.^{44,50} Greene et al.⁴⁴ did not deliver on their primary outcome measure of anxiety and report only on significant secondary outcomes. The three mixed methods studies included two of the lowest scoring papers,^{33,45} both of which contained limited reporting on methods and analysis, with a limited distinction between findings from the qualitative and quantitative methods, such that only the qualitative data could be used in this review. The remaining mixed method paper, Leonard et al.,²⁰ was predominantly quantitative in nature, with few details on analysis and interpretation for the qualitative data. For this reason, the qualitative findings from Leonard et al.²⁰ were not included in this review. No sources of systematic bias were evident across the papers.

Key themes and findings

Meta ethnography. Three main themes emerged from the meta-ethnography: *Making a practical difference* which describes the impact such work has on the immediate experiences of those facing the end of life and their caregivers; *Individual learning and growth* which describes the journey of personal reflection, development and confidence that those involved embark on; and *Developing community capacity* which refers to the impact of the work beyond the individuals involved, to the wider community where sustainable change can occur. Figure 2 provides an overview of the themes and subthemes.

Theme 1: Making a practical difference. This describes the impact the involvement of communities can have on experiences at the end of life. This was represented in both first-order descriptions of what impact the care and support had on individuals and in a second-order concept regarding the ability of basic care to bring about substantial change – ‘the ordinary becomes the extra ordinary’.²³

Table 1. Data extraction table.

Author(s) year	Aim	Country	Study design	Participants	Study quality (40)	Main findings
Benkel et al. (2009) ⁴⁵	To explore social support for bereaved friends or relatives in the first year post bereavement	Sweden	Mixed methods: survey and interviews	Bereaved friends and family Survey (n=55) Interviews (n=7)	28	The social network is relied upon to deliver the majority of practical and psychological support. Professional support is sought if the network was dysfunctional or the individual does not want to burden their network.
Burns et al. (2011) ⁵⁰	To provide information on the role of friends as caregivers	Southern Australia	Annual face-to-face health survey	2092 bereaved friends	37	Home deaths more frequent (p=0.014) and use of palliative care services higher (p=0.008) when friends are caregivers as opposed to only family members
Greene et al. (2012) ⁴⁴	To assess if caregivers perceived they were better supported and less anxious in their roles if they accessed a community network facilitator	Southern Australia	Quasi-experimental, single-blind design, pilot study	66 caregivers of palliative care patients	35	Improved within-arm changes for carers in intervention group: reduced fatigue (p<0.05), feelings of isolation (p<0.01), improved support from others (p<0.01), confidence in asking for assistance (p<0.05), ability to find resources (p<0.001). Manageability of care significantly improved in control arm (p<0.05). No between-arm differences
Horsfall et al. (2012) ²³	To understand the quality and effect of caring networks and the impacts for family, friends and the wider community	Eastern Australia	Qualitative study including individual and group interviews	94 participants in 17 caring networks	33	Four main themes: it takes a community, resisting isolation and staying connected, the ordinary becomes the extraordinary and developing death literacy
Jack et al. (2011) ²⁵	To evaluate the impact of the palliative care community volunteer programme	Uganda	Stakeholder evaluation through interviews and focus groups	21 patients, 32 volunteers and 11 hospice staff	32	Three main themes: impact on patients and families, education and support and a bridge to the hospice
Jack et al. (2012) ⁴³	To explore the personal impact of being a community volunteer worker	Uganda	Qualitative methodology using semi-structured interviews	32 volunteers and 11 hospice workers (same dataset as Jack et al. 2011)	33	Two main themes: impetus for becoming a volunteer and personal impact of being a volunteer
Leonard et al. (2013) ³⁰	To describe caring networks, to determine whether community development can be demonstrated through caring and to understand the role of social network analysis in this context	Eastern Australia	Mixed methods: focus groups discussions and participatory network mapping	76 current or bereaved carers and their networks, one patient	34	Quant size of networks increased from T1 to T2 (p<0.05) with a decrease in transiency (p<0.01) Qual: increase in number and quality of relationships and loss of relationships
Seymour et al. (2013) ²⁸	To report on volunteers' perspectives on a peer education initiative, their feelings about becoming peer educators and the community engagement activities they had engaged in	United Kingdom	Participatory action research with mixed methods of data collection	Peer educators 20 in focus groups 25 in interviews 24 survey respondents	27	Three main themes: sharing concerns and anxieties, developing a new understanding and personal and emotional implications. Survey data of poor quality – not extracted

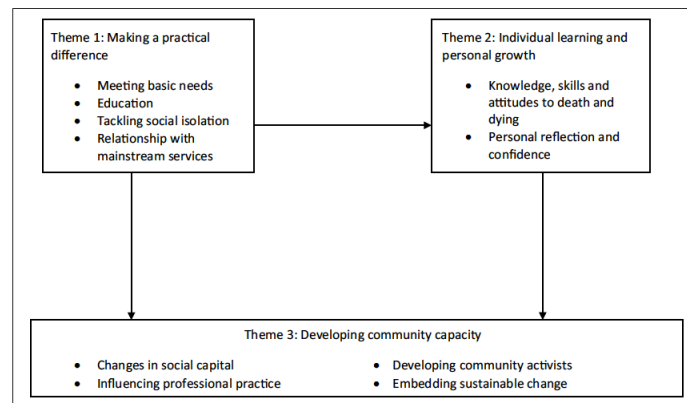


Figure 2. Themes from meta-ethnography regarding community action in end-of-life care.

Four subthemes illustrate this theme. The first, 'meeting basic needs', describes the practical tasks that communities are faced with and the impact meeting those needs has on the individuals and their families. Communities may be confronted by a series of urgent needs, relating to basic human requirements for food, water and shelter. Meeting these basic human needs would not be classed as end-of-life care but were recognised as essential support provided by communities. This subtheme was strongly represented in the papers from low resource settings^{25,43} but also featured in more developed contexts²³ and included the perspectives of both those giving and those receiving the support:

I did not have money to buy any food, the volunteer gave me money, even prepared food for me to eat – at the next visit she brought me a skirt and a blouse.²⁵

She didn't need massage or mediation lessons, she needed firewood.²³

Respondents detailed the basic nursing care that was provided. This included physical care such as wound dressing, and support for the family such as respite:

She made sure the wound does not smell.²⁵

I asked her to give some respite when Mum and Dad are out ...²³

Some impact was achieved by attending to psychological needs. A range existed of the support that was offered, from lay to semi-professional:

... we were lucky to have a very good female priest who we could talk to before the funeral ... so I felt a great deal of support and sense of community.⁴⁵

The Volunteer she encouraged my mother to stop worrying and told her that she did not think I was going to die soon.²⁵

The second subtheme, 'education' describes how, through education and awareness-raising, community members helped individuals and family carers to change their experiences of care and illness. For some, this was related to symptom control support:

They counselled me about the drugs because I had already lost hope in life.²⁵

For others, it was the sharing of practical tips and knowledge that made the caring process easier:

You kind of gleaned bits from everyone who came in ...²³

The wider community was also trained and mobilised around individuals and their families, to support the caring process:

... we are training these people who are caring for these patients – so you can change them and they die in a good way.²⁵

'Tackling social isolation', the third subtheme, was seen by participants as an important issue, both for individuals with a life-limiting illness and their carers:

I have helped some families, whereby some of the patients have been isolated in their room ...²⁵

In their second-order interpretation 'resisting isolation and staying connected', Horsfall et al.²³ recognised the central role the community plays in preventing or alleviating social isolation.

The fourth subtheme was 'relationship with mainstream services'. In undertaking these caring and supportive roles, community members were forced to consider their position relative to mainstream healthcare services. This subtheme contained some diversity and represented a refutational theme. Some community members felt that their responsibility was to work in partnership with existing services, to support and enhance their work:

We are working hand in hand with them – we cover the ground.²⁵

Others felt that mainstream services were failing them and that their job was to work outside that system:

... she was dying and not fast enough for the hospital system and they kept sending her home ... it was very distressing and without any knowledge I decided that we could do better and brought her home ...²³

Within this subtheme, two second-order themes emerged from two papers, illustrating the differing views presented by respondents – 'a bridge to the hospice'²⁵ and 'resisting the system'.²³ The two studies were conducted in different contexts, but it illustrates the positioning that community members must consider when embarking on this work and that the relationships between communities and professional services must be negotiated.

Theme 2: Individual learning and personal growth. The second theme explores the personal impact of being involved in this work. It includes impacts on the carers and family members, the person with a life-limiting illness and individuals in the wider community. It comprises two subthemes. The first 'knowledge, skills and attitudes to death and dying' captures the effect of direct experience or education on individuals' understanding of and thoughts about death and dying. Of particular note was the change in attitudes to dying at home, with respondents describing how the experience of caring for someone at home made them realise it was possible:

Even Mum did not think she was allowed to die at home ...²³

The second subtheme, 'personal reflection and growth', relates to the impact participants' experiences had on them personally, either in reflecting on past bereavements, their thoughts regarding their own deaths, or feelings of satisfaction, pride or improved self confidence that the caring or training experience generated:

... on a personal note, I too have taken notice of what I've learned from here, and I've made all my arrangements ...³³

There's a selfish act in caring ... you're learning more about what it is to live.²³

Theme 3: Developing community capacity. This theme describes the impact that is evident beyond the individuals involved in a specific case of caring, or an educational initiative. These changes act to embed this work in the wider community and make use of the skills and capacity that have developed in relation to specific situations. This is an integral component of a new public health approach; the ripple effect moves the work beyond improving experiences for individuals to influencing community change. This theme had four subthemes. 'Changes in social capital' described the often positive but occasionally negative impact on the nature, strength and number of relationships that being part of a caring network had led to. Examples of stronger relationships were given, beyond immediate contacts, and of wider trust within the community being built:

The community has more trust and confidence in those volunteers ...⁴³

The second subtheme, 'influencing professional practice', describes the further impact this work can have on professionals, through working together, feeding back or influencing them directly:

... it [has] made it seem like something more natural to talk about, not to feel so awkward about discussing end of life matters and decisions ...³³

A further subtheme, 'developing community activists', described how some felt their experiences prompted them to look for wider outlets for their acquired skills or capacities. Participants described how the personal impact of being involved in such work gave them the confidence to take the learning out into the community. Some remained within the end-of-life care field but others took on more general, civic roles:

I'm very proud to see her as an advocate for other people and using her experience to be an enabling thing in community for others.²³

... some of them [community volunteers] have even had the chance to join politics as a result of their voluntary work.⁴³

The final subtheme, 'embedding sustainable change', describes how participants attempted to change or tackle the structures in their community that were limiting good care for those at the end of life. Examples include lobbying local government, hosting community education days or taking part in research studies:

We literally pressed our PCT to get an [end-of-life care] strategy together ... we said okay we're going to hold an information day and we will invite them to come and talk.³³

A second-order interpretation from Seymour et al.³³ was that this type of sustainable action was only possible when the community members were embedded in a

strong social network and could draw on social capital and resources.

Line of argument synthesis. A meta-ethnography can produce a 'line of argument' which draws together the themes that emerged from the papers and represents a new way of conceptualising the collective data. The line of argument for this meta-ethnography is as follows.

Communities can come to take responsibility for end-of-life care issues in a variety of ways – through providing support, direct experience or through education. Those supporting others are presented with a range of needs that, once met, lead to the improved experiences of those being supported and the acquisition of new skills and knowledge by those helping. However, when community members enter the work, the experiences of being involved lead to personal reflections, learning and growth, transforming the individual as a result. Furthermore, changes can be detected beyond the immediate caring networks or individuals involved. Both the direct experiences of supporting those at the end of life and undergoing training around such issues ripple out into the wider community, producing structural and communal changes that embed the work in the fabric of the community.

Quantitative results

The three papers containing quantitative findings^{20,44,50} looked at the impact of engaging communities in end-of-life care from different perspectives, meaning a synthesis of the data from the individual studies is not possible. Leonard et al.²⁰ looked at changes in the social networks surrounding family carers and found that the size of networks increased during the caring experience ($p < 0.05$) but also found that the transitivity, or balance and reciprocity in the relationship between three people, decreased in the sample ($p < 0.01$). They suggest that this was due to the large number of new members joining the group who were only connected to the main carer, rather than having the time to establish stronger and more reciprocal relationships with other network members.

Greene et al.⁴⁴ focused on the impact of a specific intervention aimed at supporting family carers. They conducted a single-blind controlled study, where the intervention involved matching carers in the intervention group with a network facilitator. They demonstrated that carers in the intervention arm showed significant within-arm improvements in fatigue ($p < 0.05$), feelings of isolation ($p < 0.01$), sufficient support from others ($p < 0.01$), confidence in asking for assistance ($p < 0.05$) and ability to find resources ($p < 0.01$). There were no between-arm differences. In the control arm, manageability of care improved ($p < 0.05$) while it worsened in the intervention arm ($p < 0.01$). One explanation postulated for the lack of a between-arm difference was that the action of undertaking assessments and

surveys can constitute an intervention in itself and, as such, may have contributed to an effect in the control group. One reason the authors gave for the improvement in the manageability of care in the control arm, with a worsening in the intervention arm, may be that the process of organising and managing a network of friends and community members actually involved more work and contributed a degree of stress.

The paper by Burns et al.⁵⁰ examined the role of friends as caregivers for people with a terminal illness. In a large sample, they found that home deaths were significantly more likely when friends were caregivers ($p = 0.014$), as opposed to only family members and the rate of palliative care use was higher when friends/others were the caregivers ($p = 0.008$). Age, gender and illness were controlled for. The authors described how this data may suggest that people may be turning to wider social networks, beyond the family, and that this change may be influencing experiences and practices at the end of life.

Synthesis of findings

The three quantitative papers take different angles of community involvement in supporting those at the end of life and as such stand separately. However, when these findings are mapped onto the themes from the meta-ethnography, greater insight is afforded and a broader understanding of the contribution of the differing findings can be appreciated. For example, the findings from Greene et al.,⁴⁴ that having a facilitated network improves the experiences of carers, reflect the qualitative findings described in theme 1, *Making a practical difference*, with networks practically changing the experiences of carers. The improvements in confidence and ability to find resources described by carers in Greene et al.⁴⁴ are congruent with the personal developments in knowledge and attitudes described in theme 2, *Individual learning and personal growth*. The demonstration of increased numbers of home deaths and increased use of palliative care services when friends form part of a supportive network⁵⁰ again resonates with theme 1, as networks can work with the mainstream system to support more joined up care. We cannot tell whether the increased numbers of home deaths were through participation with mainstream healthcare or despite it. We can infer that the increased use of palliative care services in this cohort points to this being a cooperative rather than a resistive effort on the part of the community.

The increase in network size from Leonard et al.²⁰ supports the change in social capital from theme 3, *Developing community capacity*, although the decrease in transitivity, or reciprocity between people, suggests a more complex relationship. This was highlighted in the subtheme *changes in social capital*, where although stories existed of relationships being built and strengthened through the process, there were also examples of relationships that had been

damaged. The finding from Greene et al.,⁴⁴ of the decrease in manageability of care when a network was involved, may also shed light on this, as it suggests that being part of or managing a network caring for someone at the end of life can place a strain on participants, particularly the family members.

Discussion

This systematic review describes and demonstrates the impacts that can follow from supporting community action at the end of life, an important component of a health-promoting approach to end-of-life care. This is significant as it is a field with few outcomes demonstrated thus far, but with a rapidly developing interest in what the approach might achieve. This result is congruent with the broader literature, which suggests that engaging communities in health matters leads to improvements in health and wellbeing, capacity and longer term community change.^{10,11,13} Health promotion initiatives are acknowledged as exerting influences on a range of stakeholders, and this review permits an overview of the impacts that can occur with this work. This overview is important for practitioners in the field, as interventions and evaluations can be focused on specific outcomes.

This review demonstrates the contribution mixed methods can make to the evaluation of a field such as health promotion. The value of using mixed methods has been acknowledged in health promotion in general.^{51,52} The qualitative findings provide a depth of meaning and contextual richness to the work, while the quantitative findings allow an understanding of the causation of specific outcomes and the strength of specific relationships in the field.

The first theme, *Making a practical difference*, describes the actions that communities undertake when faced with supporting people at the end of life. Much of this work would not be considered to be end-of-life care, and would constitute more general forms of community aid. Communities respond to the varied needs they are presented with and their input is not limited by professional boundaries. This has implications for training and risk management of community volunteer programmes. Attempting to limit the care communities provide to end-of-life care only could be problematic when communities are in control of the support they provide. This can and has led to a broadening of the understanding of the term palliative care or end-of-life care. In Kerala, India, the community provides a large component of palliative care services and, as the volunteers are answerable to the community, services respond to new needs presented. In some cases, communities have moved into community psychiatry or chronic renal disease, as these were the most pressing issues communities were faced with. In the words of one community volunteer, 'we are trained to diagnose

suffering, not diseases'.⁵³ Similarly, many of the broader problems facing communities with regard to the end of life are not remedied by supporting one family at a time. This work may act as a catalyst for individuals and community organisations to begin campaigning on other social platforms for social change. It is not possible to view end-of-life care issues as separate from other social issues facing communities, such as poverty, education and inequity.

Limitations

This review is based on the published literature relating to community action in end-of-life care. Clearly there are other health promotion outcomes and applications described in the *Ottawa Charter*,⁴ that might be assessed as part of public health approaches to end-of-life care – education, policy developments, re-orientation of service designs or development of personal skills. This review benchmarks the published literature available at this point on strengthening community action but recognises that assessing the other dimensions of health promotion will become possible as the field matures and expands. Furthermore, outcomes in health promotion interventions are known to impact on a wide range of anticipated and unanticipated stakeholders and over variable time periods. The articles in this study looked at pre-selected participants and over short time frames. There may be impacts felt beyond these participants and beyond these time periods that have not been collected. The inability to capture these potential impacts is acknowledged in this review, as is the prospect that future research will take this into account. The quality grading tool was selected to be applicable to the diverse methodologies represented in the selected papers, but may have limited generalisability by not using criteria specific to particular methodologies. Additionally, quality grading exercises are acknowledged to be exercises in grading the quality of reporting rather than the quality of the actual study carried out.

This review focused on impacts relating to community action in end-of-life care but the results spanned beyond this, into other pillars of the *Ottawa Charter*, such as the development of personal skills, building healthy public policy and reorient health services. It is therefore conceivable that impacts relating to community action may be found following interventions under the other pillars and these have been missed by the specific focus of this review.

Conclusion

Issues of social isolation, carer support, personal and community capacity and wellbeing increasingly feature in policy documents for end-of-life care. This review shows that work that engages communities can meet these goals, and that the positive impact can be demonstrated, even at

this early stage of development. This has important implications for policy makers, practitioners and researchers, first that such initiatives can deliver on these complex goals and second that it is possible to measure and capture the impact. This should comprise an integral component of this work going forward.

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Appendix I*MEDLINE search strategy (1966–March 2015)*

(Public Health exp. OR Health Promotion exp. OR Social Change exp. OR Social Support exp. OR new public health.mp.
OR community development.mp. OR community participation.mp. OR community engagement.mp. OR compassionate
communit\$.mp. OR social network.mp.)

AND

(Palliative Care exp. OR Terminal Care exp. OR Hospices exp. OR end-of-life care.mp. OR incurable.mp.)

AND

(impact.mp. OR measure\$.m_title OR outcome\$.m_title OR evaluat\$.m_title)

Research in public health and end-of-life care – Building on the past and developing the new

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Introduction: Public health approaches offer the opportunity to move beyond clinical and health services approaches to end-of-life (EoL) care, to focus on whole populations, individuals and communities rather than patients and carers. They also allow concepts such as capacity, resilience, and wellbeing to come to the fore.

Methods: This paper, drawing on the experience of a diverse group of academics and practitioners from three countries in Europe, considers the research challenges related to examining new public health approaches to EoL care and how learning from more traditional or classic public health research can influence a future research agenda. Additional opportunities provided by the new public health approach to broaden learning and participation in research are considered.

Results: By bringing together strong traditional methods such as analysis of longitudinal population-level data with participatory approaches that draw on communities' experience and aspirations for care, the authors suggest that new and improved opportunities exist to evaluate the impact of participatory approaches.

Discussion: In conclusion, the paper urges researchers from classic and new public health to work in partnership to generate and respond to the emerging research agenda around new public health initiatives. There is much to be learned from both.

Keywords: Public health, Health promotion, End-of-life care, Research methods

Introduction

An increasing awareness of the relevance of public health approaches to end-of-life (EoL) care is beginning to trickle into policy and practice, as the limitations of a clinical or health service approach to EoL care are realized.^{1,2} Public health approaches offer a variety of opportunities including the possibility of engaging with people beyond the limited patient–professional interaction. Focussed on total populations or communities, rather than just persons at risk, these tools allow the recognition of those who do not receive services – ‘the hidden publics’. They support the understanding of the wider social, environmental, or physical determinants of health and move beyond disease to encompass wellbeing, resilience, and capacity. In addition, they support non-professional actors in EoL care and mitigate the impacts of life-limiting disease through prevention, early intervention, and

harm reduction. In the experience of the authors, their nature is broad; drawing together the more traditional techniques like epidemiology with newer approaches, such as community-led participatory projects.

Despite the promise of a rich start and related increasing attention on the part of clinicians, policy makers and academics, there is little evidence of a dynamic research agenda to measure and evaluate the proliferating new public health efforts around EoL care. In an effort to redress this gap in a small way, the authors came together to consider ways in which they could conduct stringent research to better understand and evaluate efforts to implement change in EoL care on a community level. We come from different countries, with different professional backgrounds and research experiences. Our starting point is the assumption of the need for a public health approach to complement clinical EoL care research in general, and of the need to work to address emerging questions related to new public health approaches in particular.

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In this article, we aim to consider how creative and complementary combinations of ideas, approaches, and methods from both traditional (hereafter known as classic) and new public health might advance the field of public health in EoL care.

Making a case for a public health approach to EoL care

Public health can be defined as the combination of sciences, skills, and beliefs directed towards the protection, promotion, and restoration of people's health through organized collective or social actions.^{1,3} Health, in line with the WHO definition, is seen not as the mere absence of disease or infirmity, but as a state of complete physical, mental, and social well-being.⁴ Accordingly, the promotion of health is not seen only as a curative or restorative approach to illness or infirmities due to illness, but also includes attention to the broad concept of wellbeing, including its social, physical, and mental components.^{5,6} Public health approaches in EoL care focus on improving and maintaining wellbeing for dying people or those affected by dying, death, and bereavement. Public health can be regarded as the collective counterpart to individual patient-care; rather than focussing on the health of individual patients and their families, the focus is on the health of a population, be it local, regional, or national.

Making a case for a different approach to research

We argue that an alternative approach to research is necessary because the predominant patient-care approach considers only a limited number of people facing the challenges of a life-threatening or life-limiting illness. The dominance of the biopsychosocial model of research within EoL care has led to an almost exclusive focus on the patient-professional caregiver relationship and on health service or professionally based interventions for implementing improvement.³ The most common approaches applied in EoL care research to date remain focussed on individuals, and specifically those receiving health care as patients. Moreover, classification is by healthcare service utilization, or by a defined biopsychosocial risk such as a specific and documented symptom. While reductionist, this model has distinct advantages for research with pragmatic reasons for its adoption; it allows a delineated focus on more readily investigated aspects of care and fits better within the epistemologies and methodologies of empirical quantitative EoL care research. Moreover, it has benefits as a model for practitioners as it allows a focus on the particular aspects of health services that they may want to change. However, it also has disadvantages. It reinforces the dominance of

healthcare professional perspectives about EoL care and the representation of 'patients' as passive recipients of care. In addition, it remains blind to many aspects of health beyond those within the mandate of healthcare services.

Making a case for bringing together classic and new public health approaches in EoL care

Classic public health approaches to EoL care comprise monitoring and assessment of the circumstances of, and health and social problems associated with, life-limiting disease, dying and living with loss, as well as planning services, policy and laws accordingly. In contrast, new public health approaches explicitly involve the community in health promotion by enabling communities to increase control over EoL care, based on capacity building and empowerment.^{3,5}

Despite some paradigmatic differences between classic and new public health approaches, we find that they share a number of important features, for example^{1,3,7}:

- (1) their focus on total populations instead of only individuals at risk;
- (2) their challenge of the dominance of solely biomedical approaches;
- (3) their recognition of non-professional actors in healthcare alongside professional healthcare services;
- (4) the importance they place on social and economic determinants of health;
- (5) their support of action and policy change.

These characteristics suggest that a public health research approach, as compared with clinical or health service research approaches, offers more if we are interested in the broader context, that is the needs or possible health improvement of a variety of stakeholders involved in dying, death and EoL care. Arguably, a public health research approach addresses issues and assets within the full population of interest, not just related to particular individuals within it (Fig. 1). This ambition leads to several research challenges, for example how to include the many different and often 'hidden publics', and demands that a wide variety of different research designs, sampling approaches and methods be applied to achieve this. We are convinced that public health approaches have much to contribute to a palliative and EoL care research agenda, if translated for use with appropriate epistemological and methodological choices, options, and operationalization.

The challenges of researching new approaches to public health

The new public health approach, although emerging as a movement from the mid-1980s, is a relatively new field in EoL care research. The paradigm formulated a number of new directions in public health,

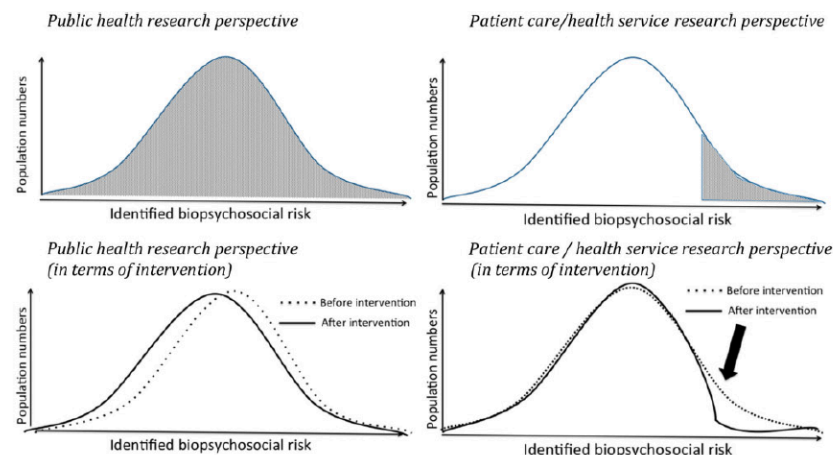


Figure 1 A public health research perspective versus a patient-care/health service perspective in EoL research. The public health perspective in EoL care research is focussed on the full relevant population, e.g. the full population of persons facing the challenges of life-shortening illness and those involved, whereas the dominant patient-care or health service perspective in EoL care research is focussed on certain 'patients' identified based on their service use or identified biopsychosocial risk. In terms of the interventions aimed at improvement of health aspects related to the end of life, the latter approach focuses on the upper end of the distribution. Interventions will, for instance, be in the form of specific medication, specific care planning strategies, or other types of interventions specifically aimed at a select patient population (such as those in a specific EoL care service). The intervention from a population/public health perspective is fundamentally different, as it targets an improvement and evaluation of that improvement at a population or community level. The types of interventions will therefore also be different, and can include information campaigns, health promoting palliative care actions, national EoL care programmes and strategies, national laws regarding palliative care regulation, availability, and access. In terms of the effects, the individual (patient-care/health service) approach can have a large effect for certain specific patients (as the intervention is specifically designed for them and can be very effective for them) but often has a marginal or no effect for the population of terminally ill patients in total. A public health population-oriented intervention may have little benefits specifically for the group at the end of the distribution but can have a larger impact on the population as a whole.

conceptualizing health as a resource for living and health promotion as the process of enabling people to increase control over their health, based on capacity building and empowerment.⁸ A guiding philosophy is that each social actor in the community, the private sector, the non-governmental sector, the faith community, and the various sectors of government, can make a potential contribution to health in an organized community effort.⁵ It moved health out of the professional arena and into the community context of everyday life. This shifted the research focus from individual risk behaviours to context and meaning. The complexities inherent to conducting such research and the additional challenges specific to the field of EoL care research mean that only a few new public health studies in EoL care have been published thus far. Some of the challenges include the long time frames required for studies, unanticipated outcomes, participants and processes, locally driven interventions that are not easily standardized or replicated, the need to recognize multiple perspectives in the work and also the difficulty of measuring concepts such as resilience,

wellbeing, and social capital. The need for the research process and outcomes to be congruent with the principles of the new public health approach, namely participation, equity, and social justice can pose further challenges. Many traditional research processes have been criticized for the disempowering effect they have on participants and studies in new public health tend to explore the issues of power that can exist between communities and professionals or researchers.⁹ In most new public health research, the process of confidence building and skill development for participants and communities is as important as the final outcome of the study.¹⁰ Furthermore, conceptual tensions can exist pertaining to the epistemology underpinning new public health research. Traditionally, this research has been based in the paradigms of social constructivism and empowerment or action methodologies, rather than (post)positivist epistemologies.

Evidence exists of a growing interest in public health approaches to EoL care and hospices, charities, academics, and community groups are driving innovation in the area.^{11,12} Even so, the majority of practitioners

and researchers remain unfamiliar with the processes and outcomes of new public health approaches and the practice examples that exist are relatively new, with early impacts and outcomes only just being realized.

Notwithstanding these challenges, evidence is emerging to support the theory and aspirations of new public health approaches across different fields and demonstrate that it is possible to conduct research in this area. Holt-Lunstad *et al.*¹³ showed the impact a strong social network has on mortality whilst Reeves *et al.*¹⁴ demonstrated the improvements in physical and mental wellbeing a strong social network confers in chronic illness, along with cost savings to formal healthcare services. O'Mara-Eves *et al.*¹⁵ conducted a meta-analysis of community engagement activities to improve inequalities in health and concluded that there is solid evidence that such activities improve health outcomes, behaviours and self-efficacy across a range of conditions. Evidence exists to support the positive health benefits of volunteering,¹⁶ the role healthy policies can play in promoting health¹⁷ and the impact of the environment and other social determinants on health.¹⁸

In recent years, evidence has emerged supporting new public health approaches as specifically applied to EoL care. Studies have included the qualitative explorations of the experiences of those involved in community projects,¹⁹ in-depth case studies of organizations adopting a health promoting approach,²⁰ action research studies^{21,22} and social network analysis.²³ The current evidence relating to community action in EoL care has been the subject of a recent systematic review which demonstrated a range of outcomes for individuals with life-limiting disease, their carers and community members including the increase in size of caring networks, decreased fatigue and isolation for family carers, and higher likelihood of a home death, alongside a number of important favourable effects explored through qualitative methods.²⁴

Although new studies are emerging, the majority of work thus far has been qualitative or exploratory in nature. There has been little systematic study of more objective outcomes and efforts at achieving systematic change on a community level. Our work together suggests that tools and methods from classic public health may be useful means for complementing the new public health approaches.

The benefits of drawing on the principles and approaches of classic public health methods

Methods and approaches from classic public health can provide important contributions to research in new public health. They offer important insights about the health problems of full communities and populations of dying individuals and those involved

and answer questions that exploratory models cannot. As a result, we recommend that researchers in the field of new public health should consider research methods and tools from all areas of public health as options for answering some of their research questions. We explore some we find pertinent below in relation to EoL care.

Death certificate data are a classic tool in epidemiology and are used as a basis for mortality statistics. They have also, however, proven to be useful tools to evaluate and monitor patterns and trends in place of death in different populations.^{25–27} Death certificate data have a major advantage in that they are at population-level and thus not limited to certain care settings or patient populations. They can therefore inform new public health endeavours, highlighting target populations who may particularly benefit from a project. Similarly, data may be followed in a longitudinal manner, to suggest potential impacts from new public health projects.

Administrative health claims data, where these are available, provide another example of population-level data. Such data have advantages similar to death certificate data but generally provide further information about formal care and medication (i.e. anything that is formally reimbursed by the health care system and recorded in the claims data). If linked with other population databases such as death certificate data, cancer registries, population data, census data on households and fiscal databases, then the use, quality and costs of EoL care can be evaluated. This can then be used to appropriately target new public health interventions but also to evaluate their influence. Furthermore, the influence of particular health service use on quality and costs of care can be studied.

Population-based surveys, based on death cases as a sampling framework, provide additional possibilities.^{28,29} Death cases, for example, provided through death certificates, allow the full population of deaths to be utilized as a sampling framework; large samples of all death certificates can be determined within a region or country in collaboration with the authorities handling the certificates. In some countries, the physician and next-of kin can be identified in this manner, and asked to complete questionnaires, e.g. about EoL decision making, circumstances of death, circumstances of care, and care provision/support for family carers. Procedures for maintaining anonymity may allow questionnaire information to be linked to death certificate information, and potentially also health claims data. The result can be an anonymous population-based, rich database of a large number of deaths representative of the full population of deaths, from which different subpopulations can be identified. This again helps identify populations who could most

benefit from new public health work and provides an opportunity to measure their possible impacts. Additionally, it provides a manner to evaluate whether the new public health initiatives in palliative care are actually including the 'hidden publics' they intend to cover.

Other interesting research methods derived from classic public health to examine large, relevant populations include the monitoring of EoL care through networks of general practitioners.³⁰ These are panels of family physicians that provide questionnaire-based information on a weekly basis about the EoL care of all deceased patients within their practice. This provides a good population-health research tool in regions where most people have and use a family physician. Additionally, classic surveys in the general population can be considered to evaluate attitudes, intended behaviour, knowledge, or experiences with death and EoL care.³¹ Such surveys allow the study of aspects regarding the EoL within the wider community, rather than only those defined as having died or terminally ill.

It is clear to us that tools from classic public health can also be used to answer new public health research questions directly. For example, structured population-based surveys can be designed with items derived from exploratory research conducted regarding the impacts of a new public health approach. This ensures outcomes are meaningful and relevant for the populations it covers, but that it provides an additional level of evidence regarding impact, beyond subjective experiences, also allowing a much larger audience to be included.

Finally, although new public health research should adhere to the principles underpinning the movement such as participation and equity, it must also speak the language and recognize the aims of many funders and policy makers that relate to place of death and health service utilization. Facilitating care or death in a person's preferred place or reducing inappropriate emergency health service use and increasing planned healthcare are priorities for governments and health services in many countries. There is evidence that new public health approaches can influence the utilization of health care services³²; it is important that those working in new public health approaches capture and demonstrate these impacts in an unequivocal way.

Final thoughts and next steps

Research methodologies from new public health and classic public health approaches should be viewed as complementary and interacting components of the public health spectrum, in which both are necessary for a concerted public health approach to EoL care.

Classic public health can be combined with new public health research in a number of ways: through highlighting populations that may particularly benefit from new public health projects; by providing longitudinal population-level data that can guide determination of the impacts of new public health work and by working in collaboration, produce rigorous population-level measures reflective of new public health ideals. New public health, in turn, brings new perspectives and offers new solutions towards achieving health-related wellbeing and involving the community as partners in their health and its research.

In order for these possibilities to be realized, it is necessary for researchers in new public health and classic public health to establish collaborative partnerships and be willing to combine and reconcile epistemological or paradigmatic differences underpinning both traditions.³³ From our collaborations and discussions, we believe that fusion of the two worlds is enriching, and well worth the effort. We will continue to find ways of navigating to a set of new truths, and invite others to do the same.

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